

'I AM NOT BEING AWKWARD'

A hermeneutic phenomenological study on the lived experiences of South Asian Muslim women with urinary incontinence.

By

Chandbi Sange

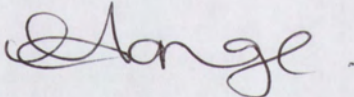
In Partial Fulfilment of the Requirements for the degree of Doctor of Philosophy
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June 2009

Student Declaration

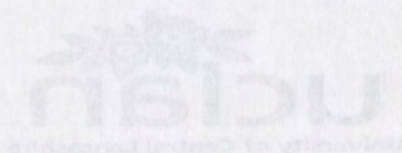
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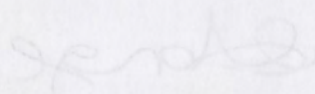
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Abstract

Urinary incontinence is not a topic that is openly discussed in any society. Rather it remains a subject that attracts social stigma, isolation and embarrassment that inevitably restricts individuals seeking health care.

Previous research conducted in this area provides useful information about the causes, complications, contributing factors, management options and outcomes. However, this research has predominantly been conducted in the White female population. Little is known about the effects of urinary incontinence within specific ethnic groups. Even less is known about the impact of UI in religiously motivated groups, such as the Muslim communities.

This study helps to explore these insights, and aims to explore the religious and cultural influences on help-seeking behaviour and decision-making within South Asian Muslim women and the 'meaning' of urinary incontinence.

This is a hermeneutic phenomenological study. Forty-one South Asian Muslim women living in the Northwest of England were interviewed using an open-ended interviewing technique. All interviews were tape recorded, and took between 1 to 2 hours to complete, as the data was allowed to unfold naturally and took a conversational style.

Twenty-six interviews were translated into English from the original language of Urdu and Punjabi, the remaining fifteen were conducted in English. Transcribed and analysed data was then interpreted using the philosophical underpinning of phenomenology.

The search for meaning in the text, and interpretation of the data resulted in the development of six major themes; 'it's the norm'; 'it's like a hush hush thing'; 'me, my family and I'; 'my religion my identity'; 'it's not cancer'; and 'get myself checked out'. Within each of the major themes sub-themes emerged.

Clearly articulated was a balancing act; on one end of the scale was the participant and their health, and on the other was the family – which included cultural traits and religious beliefs, practices and views. In order to understand what these women are describing I draw upon Antonovsky's 'salutogenesis' model and the 'five-fold medical knowledge' concept by Young, both of which gear towards the subjective interpretations that individuals apply to health, illness and wellness.

Abstract

Urinary incontinence is not a topic that is openly discussed in many cultures. It remains a subject that attracts social stigma, which may prevent individuals from inevitably restricts individuals seeking health care.

Previous research conducted in this area provides a limited understanding of the causes, complications, contributing factors, management options and quality of life. However, this research has predominantly been conducted in predominantly white populations. Little is known about the effects of living in a multicultural society on ethnic groups. Even less is known about the impact of religion on health care groups, such as the Muslim communities.

This study helps to explore these insights, and explores how the cultural influences on help-seeking behaviour and management options may vary among Asian Muslim women and the meaning of urinary incontinence. This is a hermeneutic phenomenological study. Twenty-one Muslim women living in the Northwest of England were interviewed using a conversational interviewing technique. All interviews were tape-recorded and lasted between 1.5 hours to complete, as the data was allowed to develop naturally in a conversational style.

Twenty-six interviews were translated into English for the purpose of analysis. And finally, the remaining three were conducted in English and were not analysed. Data was then interpreted using the hermeneutic phenomenological approach.

The search for meaning in the text, and interpretation of the data, was the development of six major themes: 'it's the norm'; 'it's a shame'; 'it's a private matter'; 'family and I'; 'my religion my identity'; 'it's not correct'; and 'it's a tragedy'. Within each of the major themes sub-themes emerged. Clearly articulated was a balancing act; on one hand the women were concerned about their health, and on the other was the family, which was a source of support and help. In order to understand the women's religious beliefs, practices and views, in order to understand the women's experiences, I drew upon Antonovsky's 'salutogenic' model and the 'cultural knowledge' concept by Young, both of which provide a framework for understanding interpretations that individuals apply to health, illness and disease.

A number of recommendations are made and suggestions for future research are also included as a result of the findings from this study.

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Advising the
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Communication

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2. Initial search of themes

3. Second stage of thematic development

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Recommendations for the future

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There are many people I would like to thank. Without the support and encouragement of these people my study and thesis would not have been complete.

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I cannot end without thanking my family, to my sisters, Gausiya, Shama, Shaheen and Hajira and my parents – whose constant encouragement and love I have relied on throughout this journey – thank you.

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Ubbah

Chapter 1

Introduction

Introduction to the chapter

This chapter is intended to give an overview of the study and the thesis. It will explain why this study is important and what I intend to investigate.

This chapter is developed to provide an overview as to why I think it is an area that requires researching, therefore I will present within it, the process of how I became aware of this under-researched area and how the aims were developed, refined and established.

Background of the study

In modern British society, attitudes towards many previously taboo subjects are rapidly changing. Incontinence is also gradually becoming an acceptable subject for open discussion for sufferers and professionals (Glew 1985; Horsfield 1986; Walker 1987). However, the majority of epidemiological research on urinary incontinence (UI) has been conducted on an older White population that is predominantly female (Gray 2003). Little is known about the prevalence of incontinence in non-White, younger populations. The exact prevalence of UI in the UK is under-estimated, as many individuals are reluctant to seek help for a range of reasons including shame, embarrassment and ignorance regarding availability of treatment (Norton, 1988). Studies assessing the affect of UI on quality of life have explored the subjective experience of these conditions, but have rarely addressed the importance of ethnicity or the influence of religion and culture on individuals (Chaliha and Stanton, 1999).

Urinary incontinence is distressing, unpleasant and frequently socially disruptive. As a health issue incontinence can:

- Cause skin breakdown which may lead to pressure sores;
- Be indicative of other problems in children, such as emotional problems rather than physical disorders (Fillingham & Douglas, 1997).

As a social issue, failure to manage faecal and urinary incontinence can:

- Cause emotional and behavioural problems;
- Restrict employment, educational and leisure opportunities;
- Lead to social embarrassment and social exclusion;
- Result in people moving to residential and nursing homes;

- Cause conflict between the individual and their carer;
- Cause soiling and ruin clothes and bedding, leading to extra laundry costs and increased expense for those items (Isacsson et al 1998; Minassian et al 2003).

Indeed, the potential for urinary incontinence to reduce social and emotional well-being seems obvious. Understanding the impact of UI and associated factors within any religious or cultural group is necessary to indicate how they understand and view such a condition. Bhopal (1997) states the lack of understanding of conditions and embarrassment continue to be major factors stopping people seeking help. Wilkinson (2001) also found Muslim women felt that health care professionals were not interested in their problems and did not provide adequate support, thereby restricting their ability to seek further services.

A small number of studies have examined cultural or ethnic influences on UI. Chaliha & Stanton (1999) found Muslim women reported more sexual and religious restrictions related to their UI than Hindus, Jews, Buddhists or Christians. The most significant finding in their study related to the interaction between incontinence and religious obligations, particularly for Muslim and Jewish women during prayers. The disruption of leaking urine whilst praying can have a more devastating affect on the individual's quality of life, as praying is seen as a relationship between the performer and their God (Al-Misri and Keller, 1994).

Similarly Wilkinson (2001) found Pakistani (Muslim) women with UI had distinct cultural, language and religious characteristics, which introduced further problems and made it even harder for these women to seek health care. Although these factors have been identified they have not been explored in full. This then became the aim of this research project, *'to explore the religious and cultural influences on help seeking behaviour and decision making in Muslim women with UI'*, with the purpose of developing an understanding the impact of these factors on the individual's life.

A recent study by Doshani et al (2007) titled 'culturally sensitive continence services among South Asian Indian women' found a lack of knowledge about urinary incontinence as a condition within this group of women. Doshani et al (2007) clearly articulated three specific areas that were concerns for these women namely, a) normalisation/management, b) help-seeking/access to health care, and c) suggestions to improve services. Many of the women in this study group felt that their lack of knowledge around normalising the condition caused a barrier when seeking

Cause conflict between the individual and their carer.
Cause soiling and ruin clothes and bedding, leading to extra laundry costs
and increased expense for these items (Jansson et al 1998, Milne et al
2002).

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health care. This study has been one of the significant studies on which to base this research project, however differences in the sample are clear. Doshani does not state from what religious backgrounds these women are drawn, however it can be assumed that participants were from a Hindu or Sikh background as gurdwaras and Hindu temples are holy places where this group of women are likely to attend for religious activities. Following Doshani's (2007) study, the original aim (as stated above) was refined to only include 'South Asian Muslim women'. The reason for this was due to the demographic data gained of the study site. The study was conducted in a Northwest town of England, as required by the fund holder. The demographics suggested that after the White population in this area Muslims were the second largest community residing there. The aim was then refined *'to explore the religious and cultural influences on help seeking behaviour and decision making in South Asian Muslim women with UI'*. The findings may therefore be different from Doshani's (2007) study.

One such factor and probably the one most reported in research is the inability to communicate independently in English. Literacy and the inability to read and write have also caused a barrier for many Muslim women, as does the understanding of treatment options and advice. Wilkinson and Williamson (1995) found the translation of clinical and medical terminology into other languages could cause problems, as some words are not directly translatable. This issue was explored further in this study. The sample consisted of South Asian Muslim women from the age range of 18 years and over to identify whether literacy was a concern. To begin with, a common language was identified for women likely to meet the inclusion criteria. Urdu was the main language for all participants; therefore all documentation was translated into Urdu. This included the information packs (refer to appendix six) and the advertisements for the study (refer to appendix seven).

The supervisory team identified that questionnaires that are distributed to South Asian patients with continence problems in clinics are written in English. These questionnaires form part of the consultation and provide professionals with vital information for diagnosis and management. The questionnaires are developed by the International Continence Society (ICS) and are valid and reliable measuring tools for the English speaking Caucasian population. However, their use in other populations had not been validated. The two questionnaires commonly used in clinically settings are the International Consultation on Incontinence Questionnaire-Lower Urinary Tract Symptoms quality of life (ICIQ-LUTSqol) and the International Consultation on

Incontinence Questionnaire- Urinary Incontinence Short Form (ICIQ-UI SF). In addition to the original aims of this study, translating these questionnaires into Urdu and completing the 'face validity' test was also completed. However, as the focus of the study shifted towards a phenomenological perspective, this validation exercise became peripheral to the concerns of the thesis, so it is not reported here.

Recent studies have explored whether the ethnic background of sufferers is a risk factor for developing UI. Evidence that race influences the overall risk of incontinence is mixed, although there are strong data suggesting race/ethnicity may influence the risk of developing certain types of UI (Duong and Korn, 2001; Graham and Mallett, 2001; Novielli et al, 2003; Song et al, 2005; Teo et al, 2005). For example, stress incontinence is more prevalent in White women (Bump 1993; Duong and Korn 2001; Novielli et al 2003); urge incontinence is more prevalent in black women and stress incontinence in White women (Sze et al, 2002). In relation to the Asian communities, Teo (2005) identified that Asian women had a greater incidence of detrusor over-activity and mixed incontinence than White women did. Reasons for these differences need further exploration.

Vaginal childbirth is a factor for the development of urinary symptoms. As Wilkinson & Williamson (1995) found, Muslim women tend to have larger families and are less likely to attend antenatal classes, where women are taught pelvic floor exercises that can strengthen these muscles, which can prevent or lessen the likely chance of developing UI. Haggar (1994) states that the poor uptake of antenatal classes by this group may be related to culturally driven views, as childbirth is related to sexual intercourse, making it a private topic, which leads to culturally unacceptable talk. Therefore exploring culturally taught behaviour was necessary in relation to leaking urine, and in general.

For a number of years researchers have been interested in what facilitates the use of health services; what influences people to behave differently in relation to their health. The focus has been on how people make decisions about health related issues and the factors influencing whether or not people seek help (Harding and Taylor 2002). The decision to engage with a particular source of health care is influenced by a variety of socio-economic variables including: sex, age, ethnicity, the social status of women, types of illness, access to services and the perceived quality of the service (Tipping & Segall, 1995). Help-seeking behaviour can be defined as an active rather than a passive process that involves interpreting symptoms, evaluating

Incontinence Questionnaire- Urinary Incontinence Short Form (ICIQ-UI SF). In addition to the original aims of this study, translating these questionnaires into Urdu and completing the 'face validity' test was also completed. However, as the focus of the study shifted towards a phenomenological perspective, this validation exercise became peripheral to the concerns of the thesis, so it is not reported here.

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possible responses and, finally, deciding on whether to try to alleviate those symptoms or simply to ignore them (Shaw 2001). Shaw (1999) states help-seeking behaviour is influenced by the considerations of others, for example, friends and family. However, discussing stigmatising conditions such as UI is not a norm. Many sufferers are more likely to deny and conceal such symptoms, even from significant others.

There are many influences that encourage or discourage an individual from either seeking help or going against treatment. Two such influences are culture and religion. According to Walsh (1998), religious and cultural beliefs can have positive influences on health by acting as a source of inspiration. However, Ahmed (2000) found they might also have negative influences, for example, when they are linked with guilt and punishment. Kelleher & Islam (1996) have stated that religious beliefs may create a sense of fatalism, a belief that someone or something other than the individual is in control. This identification is also called 'external locus of control' developed by Rotter in the 1950's, which refers to an individual's perception about the underlying causes of events in his or her life (Rotter, 1966) which can affect health behaviours and outcomes. Another likely influence is the affect of the condition on quality of life. However, it cannot be assumed that there is a simple linear relationship between severity of symptoms, quality of life, and help-seeking behaviour.

Significance of the study

This study is about women's experiences, there are a variety of ways of conducting such studies, one of which is the quality of life technique. 'Quality of life' is a descriptive term that is widely used and interpreted in many different ways, for example Brock (1993) defines it simply as a 'good life'. The term refers to a person's emotional, social and physical wellbeing, and their ability to function in the ordinary tasks of living. Quality of life is measured using specifically designed and tested instruments, which measure people's ability to function in their tasks of living (Abrams 2003).

These range from White population (Pinnock and Marshall, 1997; Swithinbank et al, 1999; Melville et al, 2005), in Chinese Asian women (Chaliha and Stanton, 1999; Lapitan and Chyeon, 2001; Wilkinson 2001; Jik-Joen, 2004), and black women (Brown et al 1996; Brown et al 1999; Duong and Korn 2001). However, I am not

carrying out a formal QoL study rather I intend to explore 'meaning of UI'. A literature search undertaken as part of this research did not reveal any studies linking the impact and meaning of urinary incontinence with help-seeking and decision-making behaviour related to UI in the Muslim population. Previous research has also stated religious and cultural beliefs can influence people when seeking health care (Kelleher and Islam, 1996; Walsh, 1998; Ahmed 2000). However, again, no studies have shown any comparisons relating religion and culture in South Asian Muslim women's help-seeking behaviour related to urinary symptoms.

It is commonly reported that UI is seen as a normal part of ageing and one condition that women or men accept. However the impact of UI was assessed by MaCaulay et al (1991). They indicate that one-quarter of sufferers were more likely to be as depressed, anxious and phobic as psychiatric patients. This suggests that UI is an important topic to explore as it can have a profound impact on sufferers. However the research exploring this among the Muslim communities is lacking. This does not only suggest many Muslim women do not access continence services but also that many of these women may be suffering in silence due to such beliefs. There is vast amount of literature exploring why people from ethnic minority backgrounds do not access health services, however understanding of the influence of cultural and religious influences on this process is limited. The lack of empirical research means that professionals may have only formal insights into cultural and religious influences on UI management. Therefore I will be focusing on the impact of UI on this sample and also what UI means to this group.

Statement of the problem

From the literature and through my own experiences as a nurse working with this group the following research question was finally formulated to aid the review and to develop the aim(s) of this research project: *'why are South Asian Muslim women less likely to seek help for urinary incontinence needs than White women, especially if leaking urine causes a barrier between them and performing prayers?'*

Drawing on primary evidence

Literature reviews on women and urinary incontinence revealed that a variety of factors, have been explored in several theoretical paradigms which have developed

practical support. For example the development of the International Continence Society (ICS) in 1971, as well as the official website links, namely through an experimentation design:

www.Incontact.org

www.incontinentsupport.org

www.internationalcontinencesociety.org

www.simonfoundation.org.

These websites provide support for those who suffer from urinary/faecal incontinence, and have developed through an experimentation design, for example the development of the questionnaires that measure quality of life. Existing literature and research on urinary incontinence is based on both the quantitative approach and the qualitative approach, which have both been valuable in providing evidence and new insights. A recent commentary published by Dohani et al (2008) on 'the value of qualitative research in uro-gynaecology' summaries the importance of using such an approach in the medical field. Doshani et al (2008) insist that all quantitative data are based on qualitative judgement, for example the development of the ICIQ questionnaires were generated through interviews to check the meaning of words and terms and to validate questions. It further allows a tool to unravel uncertainties and to explore the relationship of the symptoms to existing measures.

Over the last 10 years, there has been an increasing realisation that it is important not only to assess the severity of UI symptoms, using objective investigations (questionnaires), but also to evaluate the impact of these symptoms on the individual's life (subjective experience) (Kelleher et al 1997; Lemack and Zimmern 2000). The majority of these studies have generally taken an observational cross-control approach, a cohort approach or a longitudinal approach to increase the validity of such studies. However, the majority of these data draw on the feelings and beliefs gained from the White population. In this study I am particularly interested in the ideology of culture and religion and how this may impact on the lives of Muslim women when suffering from urinary incontinence and if these factors influence help-seeking behaviour. Religion and culture as ideologies can affect both the range of possible solutions Muslim women perceive for dealing with urinary incontinence and their roles as Muslim women (Kelleher and Islam (1996; Walsh 1998). These issues need to be explored in relation to the aim(s) of the study.

In order to answer the research question, it was necessary to explore why, if leaking urine was so devastating to Muslim women in relation to their religious activities, do only a small number of these women seek help.

To provide evidence of the low uptake of continence services by South Asian Muslim women, I decided to collect the demographic data of the area of study, which suggest in 2001 (date of last census) that there were approximately 77.9% White and 20.6% South Asian people (www.bwdpct.gov), including males and females. I compared this to the patients who had accessed continence services between the dates 10th January 2005 to 12th of March 2006. Overall, within the 15-month period, 4843 patients were seen in the outpatient gynaecology department at the study site. Reasons for seeking treatment were not just for urology needs, but also consisted of general gynaecology. Consultants held clinics, as did registrars and nurses. Out of the 4843 patients, 'Asian' sounding names were 519. This is not the precise number as many of these patients were seen on numerous occasions. Therefore, it appears that 1 in 10 'Asian/Muslim' women were seen in these clinics, compared to 9 in 10 women from the White population within the Northwest area.

This low uptake of services in the local area suggests many more women that are Muslim may be suffering from UI, but do not actually seek services for this problem. Gaining this evidence influenced me to explore factors that encourage some South Asian Muslim women to seek services and some not to. Strategies for increasing uptake depend on the understanding of possible barriers and facilitators. This then became the justification of exploring urinary incontinence in a religiously motivated group.

Aims of the study

The initial aim of this research study was *'to explore the religious and cultural influences on help seeking and decision making in South Asian Muslim women with UI and how these influences impact on their daily lives'*.

This aim was then broken down into separate entities and covered the following sub-aims:

1. To explore beliefs about urinary incontinence amongst these women.
2. To examine the relationship between the severity of the condition and help-seeking behaviour.

3. To understand help-seeking behaviour and decision-making among women who have received health care from continence services and women who have not received services for urinary incontinence.

The study initially included not only the views and beliefs of the South Asian Muslim women, but also the views and beliefs about the response of South Asian Muslim women as interpreted by professionals working in the continence services. As for the translation and validity checking this section of the study is not central to the focus of the thesis, which is concerned with the phenomenological meanings of incontinence to South Asian Muslim women, and not external interpretations of these meanings by others, so it is not reported here.

As can be seen in the shifting focus of the study, this research project became a journey, where the destination was ultimately determined by the 41 South Asian Muslim women who participated in the one to one interviews. In this process, I set out to explore whether religion and culture influenced help-seeking behaviour. However the narratives of the 41 participants directed the journey to their experiences and their meaning of urinary incontinence, in relation to their religion their culture and their family (pg 113-114). During the journey, the initial aim changed over time, from examining and understanding beliefs and help seeking behaviour, to an in depth exploration of *'the meaning of urinary incontinence in South Asian Muslim women'*, taking into consideration their religion their culture and their lived experiences.

Organisation of the thesis

This thesis contains fourteen chapters. In **Chapter One**, there is an introduction to the thesis, short background literature to the study, and finally the aims of this study.

Chapter two is divided into three distinct sections which present the background literature on urinary incontinence, help-seeking behaviour, culture and religion.

Section one of this chapter, presents urinary incontinence as a topic, as a medical condition, and as a personal condition, and provides details of the studies previously conducted in search of the literature gap. This section draws upon the history, the prevalence, the management, and the affect of UI on the individual sufferer's life.

Section two examines help-seeking behaviour in relation to UI. I draw attention to previously developed explanatory models that have been extensively used to predict and control behaviour and behaviour change. Service utilisation and health inequalities amongst the ethnic groups are also highlighted.

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Section three introduces the Muslim culture and the Islamic faith. To begin this section I have provided a personal perspective as I am a Muslim woman, and separating myself from this perspective is impossible, as it is a fundamental part of who I am.

The distinction between Islam as a religion and Islam as a culture is discussed, followed by the main topic in this study, Muslim women and the influence of Islam on health-seeking.

The three main areas of the literature review are immense, therefore the literature section is completed with a concluding section on how the above areas link to the phenomenon under study, to demonstrate how each area may relate to Muslim women seeking health care for urinary symptoms.

In **Chapter 3 and Chapter 4**, I explore the theoretical foundations of the study, and description of the methods and data analysis tools used. **Chapter 3** explores the basic hermeneutic phenomenological approach I have chosen. In **Chapter 4**, the methods of data collection, data analysis, the sample, the setting and ethical issues are all presented.

Chapter 5 is dedicated to introducing the South Asian Muslim women who participated in this study. Due to the sample size, I have only provided stories of ten of the women. These stories are provided to situate them as individuals. These stories outline some of the personal circumstance these women face on a daily basis.

The following six chapters present the findings of the study. Key themes are presented in separate chapters as follows: **Chapter 6** 'Me, my family and I'; **Chapter 7** 'My religion my identity'; **Chapter 8** 'It's the norm'; **Chapter 9** 'It's like a hush hush thing'; **Chapter 10** 'Its not cancer' and **Chapter 11** 'Get myself checked out'.

In **Chapter 12**, the meanings from the transcribed interviews are interpreted as the 'balancing act' that these women were describing. Two overarching themes were developed relating to, the 'meaning of illness' and 'family, religion and culture'.

The meaning ascribed by these women and to explore their 'way of seeing' I have applied the '*salutogenesis*' model and the '*five fold medical knowledge*', both of which focus on the subjective meanings or experiences rather than the explanatory models that tend to centre on an illness or a disease.

Chapter 13, provides the answer to the 'so what?' question, through my interpretations of the data and through the 41 stories. In this chapter, the implications of the findings are discussed and suggestions made for future research.

The final chapter, **chapter 14**, is a personal account of the research process. Here, I present my views, my opinions and thoughts. This chapter follows the research process and concludes with my role as a researcher, a Muslim woman and a nurse.

I have used terms throughout the thesis that may be unfamiliar. I have therefore presented them in **Appendix one Glossary of terms used** and provided explanations, to aid understanding.

Summary

This chapter has introduced the research area. The purpose of the study, the aims, and the significance of urinary incontinence in a religiously motivated group has been summarised. A summary of the organisation of the thesis has also been provided, with attention drawn towards the glossary of terms used in appendix one.

The next chapter will introduce section one of the literature review, 'urinary incontinence'.

Chapter 13 provides the reader with a detailed account of the interpretation of the data and the findings of the study. The findings of the study are discussed and the implications of the findings are discussed.

The final chapter, chapter 14, is a conclusion. In this chapter, I present my views, my opinions, and my conclusions. I also discuss the process and conclude with my views on the future of the study.

I have used terms throughout the book that may not be familiar to some readers. I have presented them in Appendix and I have provided explanations to aid understanding.

Summary

This chapter has introduced the reader to the study and the significance of the study. The study was conducted to investigate the relationship between the variables and the significance of the study was discussed. A summary of the study was provided.

The next chapter will introduce the reader to the study and the significance of the study. The study was conducted to investigate the relationship between the variables and the significance of the study was discussed. A summary of the study was provided.

Continued.

Chapter 2: Literature Review I

Urinary Incontinence

In the previous chapter, I have outlined the significance of conducting the study, and why I think it is an area that needs exploring. A flow of the thesis is provided to allow an overview of what will be covered in the following chapters.

Previous research on urinary incontinence in the UK has been mainly carried out within the White majority of the population with very little attention given to the ethnic minority populations.

Introduction to the Chapter

In this chapter I will provide an overview of urinary incontinence. There are a number of classifications, which will be covered in this chapter. However, for the purpose of this study I have not concentrated on one specific classification.

Urinary incontinence is a common problem, one that is unpleasant and has distressing symptoms for the individual; it affects women in greater numbers than men (Norton, 1986). Due to the nature of the subject area it is not surprising the sufferers are unwilling to discuss this problem with others including health professionals (Bates et al 1977, Norton 1982; Herzog et al 1989; Ashworth and Hagan 1993; Shaw 2001; DoH 2000; Abrams et al 2006). It is not a disease in itself but a symptom of many possible underlying problems, which means it is often poorly understood. Previous research into urinary incontinence has covered areas such as medical treatment options (Abrams et al 2005), feelings, and beliefs about urinary incontinence (Beder 1990, Ashworth and Hagan 1993, Barrett 1993, Shaw, 1999, Bogner 2004). However, this previous research has mainly encompassed White elderly female populations (Gray 2003). To date not as much is known about urinary incontinence in the young, male or ethnic minority populations.

In this chapter, the literature on urinary incontinence has been systematically reviewed in relation to the following: prevalence studies worldwide, incidence, and burden of incontinence, assessment, promotion and management of continence. The aim of this chapter is to gain an understanding of urinary incontinence. Initially international data is presented. I have then narrowed the search to the studies conducted in the UK, and then specifically to the ethnic minority populations. To

In the previous chapter, I have provided a brief overview of the research area and why I think it is an area that needs to be explored. I have also provided an overview of what will be covered in this book. Previous research on urinary incontinence has been limited, particularly within the White majority of the population, and there is a need to explore minority populations.

Introduction to the Chapter

In this chapter, I will provide an overview of the research area and why I think it is an area that needs to be explored. I have also provided an overview of what will be covered in this book. Previous research on urinary incontinence has been limited, particularly within the White majority of the population, and there is a need to explore minority populations.

Urinary incontinence is a common condition that affects many people, particularly older people. It is a condition that can have a significant impact on a person's quality of life. Previous research has shown that urinary incontinence is more common in older people, particularly in women. However, there is a need to explore urinary incontinence in minority populations, particularly in Black and Asian populations. This is because there is a need to understand the experiences of these populations and to develop interventions that are tailored to their needs. Previous research has shown that urinary incontinence is more common in older people, particularly in women. However, there is a need to explore urinary incontinence in minority populations, particularly in Black and Asian populations. This is because there is a need to understand the experiences of these populations and to develop interventions that are tailored to their needs.

In this chapter, the research area is explored in more detail. The research area is explored in relation to the research objectives and the research questions. The research objectives are to explore the experiences of older people with urinary incontinence, to explore the experiences of older people with urinary incontinence in minority populations, and to explore the experiences of older people with urinary incontinence in minority populations. The research questions are to explore the experiences of older people with urinary incontinence, to explore the experiences of older people with urinary incontinence in minority populations, and to explore the experiences of older people with urinary incontinence in minority populations.

begin with I will introduce urinary incontinence, what it means to be incontinent, and why this is a burden on many sufferers.

What is incontinence?

Watson (2001) defined incontinence, as an 'inability to control natural functions or discharges' of the body. It is a common belief that incontinence is a problem that elderly people only suffer, and this is consistently reported in research (Norton, 1986, Abrams 1995, Aron et al 1998, Shaw 2001). Incontinence can happen to anyone of any age and at any time in his or her life. Whether an individual is deemed to be 'incontinent' depends very much on their own definition, and the amount of leakage. People can suffer from urinary or faecal incontinence. Johanson & Lafferty (1996) stress that while urinary incontinence is more prevalent in the population than faecal incontinence; the latter is a much more distressing problem. Thomas et al (1984) similarly state that faecal incontinence is socially more unacceptable than urinary incontinence and raises a strong emotion among those who have to deal with it, whether that is the sufferer or their carers.

In addition, Norton (1986) states whatever type of incontinence the individual is suffering from, urinary or faecal, the term incontinence does not relate to the fact of excretion, but with its location and timing. For example, it is socially acceptable for an infant to pass urine or faeces in their nappy, as the physiological systems of the infant are not mature enough to have control over their bladder or bowels. The control over bladder and bowel sensation is therefore socially acceptable, the norm, and a taught behaviour. Adults who do not develop this sensation or have lost the ability to control it are consequently, labelled 'incontinent' (Ashworth and Hagan, 1993). Cortis (2003) suggest having control over urinary elimination is an expected norm in every society. For this reason, people do not disclose or admit urinary symptoms for the fear of being classed 'abnormal'.

As this study is specific to 'urinary incontinence', faecal incontinence will not be covered in the rest of this chapter.

Function of the bladder

The bladder is a hollow organ that can hold up to approximately 800mls of urine (Smart, 2001). The bladder expands as it fills with fluids, and pain receptors are sent

begin with I will introduce some background information on the condition and why this is a burden on many people.

What is incontinence?

Watson (2001) defines incontinence as the 'inability to control the discharge of the body's fluids'. This definition is broad and includes elderly people only suffering from urinary incontinence and faecal incontinence. Although it is a broad definition, it is not meant to be any age and it may be a bit confusing as it is not clear what is meant by 'incontinence' depends very much on the context in which it is used. People can suffer from general incontinence, which means that they cannot control their urine or stool. This is often the case with urinary incontinence, which is a common condition. Incontinence, the term used by the medical profession, is a general term that simply state the fact that a person is unable to control their urine or stool. Incontinence and refers to a range of conditions that affect the ability to control the body's fluids. It is the ability to control the body's fluids that is the subject of this study.

In addition, Pichon (1995) states that incontinence is a condition that is suffering from urinary or faecal incontinence. This definition is broad and includes elderly people only suffering from urinary incontinence and faecal incontinence. Although it is a broad definition, it is not meant to be any age and it may be a bit confusing as it is not clear what is meant by 'incontinence' depends very much on the context in which it is used. People can suffer from general incontinence, which means that they cannot control their urine or stool. This is often the case with urinary incontinence, which is a common condition. Incontinence, the term used by the medical profession, is a general term that simply state the fact that a person is unable to control their urine or stool. Incontinence and refers to a range of conditions that affect the ability to control the body's fluids. It is the ability to control the body's fluids that is the subject of this study.

As this study is specific to urinary incontinence, the term 'incontinence' is covered in the rest of this study.

Function of the bladder

The bladder is a hollow organ that is part of the urinary system. It is located in the lower part of the abdomen and is responsible for storing urine. The bladder is a hollow organ that is part of the urinary system. It is located in the lower part of the abdomen and is responsible for storing urine.

to the sacral bladder centre in the spinal cord via the sensory impulses. The impulses of the bladder continue and become stronger, until an appropriate environment is reached where urine can be released. When the sphincter muscles are relaxed, urine passes out of the bladder. Once the individual reacts and empties the bladder, these impulses automatically discontinue, until the next time the bladder becomes full (Smart, 2001). Incontinence can then be described as the situation when an individual has lost this ability to recognise and react to the sensory impulses.

Norton (1986) identified three broad categories, which can have an impact on the normal bladder function; physiological bladder dysfunction; factors directly influencing bladder function; and factors affecting the individual's ability to cope with bladder function. The first indicates an abnormality in bladder function, for example the failure to hold urine or a failure to empty the bladder. The second factor indicates medical conditions that can have a direct impact on the urinary system, which include urinary tract infections, constipation, medication or operations. The final factor relates to physical, emotional and environmental factors that can have a direct impact on the sufferer's life (Norton, 1986).

There are different reasons, why people lose control of their bladder or never acquire it. There are also different types of urinary incontinence, although the symptoms may be similar (Norton, 1988), as will be discussed later in this chapter.

Definition of Urinary Incontinence

It has been suggested that clear definitions and sound knowledge of UI have been lacking. This has led to misinformation and certain mistaken assumptions such as incontinence being untreatable (Dr. Avicenna in Cron, 2003). These assumptions are now being challenged. Definitions have ranged from any leakage (Foldspang et al 1992; Maggi et al 2001; Rortveit et al 2003) to specific types of leakage for example on exertion or at night (Hunskar et al 2004; Irwin et al 2005; Biri et al 2006).

Table one identifies some of the definitions applied to studies on urinary incontinence.

Table 1 Definition of urinary incontinence

Author	Definition
International Continence Society (ICS). Abrams et al (1979)	'A condition of involuntary urine loss that is a social or hygienic problem and which is objectively demonstrable'.
Thomas et al (1980)	'Involuntary excretion or leakage of urine in appropriate places or at inappropriate times twice or more a month, regardless of the quantity of urine lost.'
Andersen (1988)	'An involuntary loss of urine which is objectively demonstrable and a social or hygienic problem'.
Norton (1996)	'The involuntary loss of urine which is objectively demonstrable and a social or hygienic problem'.
Pace et al (1998)	'The inability to control urine flow'.
International Consultation on Incontinence (ICS) Abrams et al (2002)	<p>'The complaint of any involuntary loss of urine' (2002). A definition suitable for epidemiological studies.</p> <p>'Involuntary loss of urine that is a social or hygienic problem' (2002).</p> <p>Separate definitions are provided for specific symptoms: urge, stress, mixed, nocturnal enuresis, post-micturition dribble, and overactive bladder.</p>
NICE (2006)	'The complaint of any involuntary leakage of urine'.
NHS direct (2008)	'The unintentional passing of urine'.

In 1971, Eric Glen founded the International Continence Society. This society was previously known as the Continent Club. The first meeting in 1971, attracted over 60 participants from different countries. The interest of this society was, and is, to study storage and voiding function of the lower urinary tract, diagnosis and the management of lower urinary tract dysfunction, and to encourage research into pathophysiology, diagnostic techniques and treatments. The meetings have continued on an annual basis. The first reports were published between 1976 and 1981. Evaluation and management of the incontinent patient were and are provided in their reports. The committee has had a strong influence and the authors are chief commentators in this field.

The ICS committee was the first to provide a standardised definition of urinary incontinence: '*a condition in which involuntary urine loss is a social or hygienic problem and is objectively demonstrable*' (Abrams et al 1979). Prior definitions consisted of what health care professionals and authors had felt appropriate. Although this definition has been used throughout literature, many authors have found it unsuitable. For example, Foldspang and Mommsen (1997) found the definition did not specify the terms that 'social' 'hygienic' and 'problem', and state that it is impossible to demonstrate urinary incontinence in an objective manner.

Following on from this, the ICS in 2002 revised their definition to a much broader one, which would be suitable for epidemiologic studies and comparisons (see above table). Abrams et al (2005) in the Third International Consultation on Incontinence provided professionals with a summary of recommendations, evaluation techniques and treatment options for urinary incontinence, pelvic organ prolapse and faecal incontinence. This document also presents definitions for the different types of lower urinary tract symptoms, which direct professionals in the diagnosis, assessment and management stages. Part one of the document is centred on these definitions, which are divided into storage symptoms and voiding symptoms (Abrams et al 2005).

The 2005 definition is very broad. The term '*any*' (see table one) can be interpreted as leakage that may have only occurred once in a lifetime (Minassian et al 2003). Again, the interpretation is left to the interpreter. The authors have argued that a broad definition is better as it gives professionals a chance to explore other aspects of urinary incontinence in order to promote better understanding and channel treatment appropriately (Abrams et al 2002, 2005).

To summarise, physiologically, urinary incontinence is a storage problem, as the bladder has lost its capacity to maintain and recognise symptoms. The type of incontinence depends on the individuals symptoms. However, textbooks, government documents and guidelines have used slightly different terms for the types of urinary symptoms. For example, 'stress incontinence' can be referred to as 'genuine stress incontinence'; 'urge incontinence' as 'urgency urinary incontinence'. Detrusor instability is also referred to as urge UI. Sub-categorisation of urinary incontinence can be summarised as follows:

a) According to Lagro-Janssen et al (1992) **stress incontinence** results from a failure of the urethral sphincter to remain closed when sudden abdominal pressure on the bladder occurs, e.g. during coughing, sneezing or laughing.

- b) **Urge incontinence** results from the contraction of the detrusor muscle of the bladder as if to urinate, when only small amounts of urine have accumulated in the bladder (Norton, 1988).
- c) **Overflow incontinence** occurs because of urinary retention or constipation (DoH 2000).
- d) **Reflex incontinence** may occur because of damage to the spinal cord and loss of sensation to urinate, leading to failure to inhibit the simple reflex arc (Anderson 1988).
- e) **Nocturnal enuresis** is the term for urinary incontinence, which occurs during sleep (Skoner & Haylor, 1993). **Nocturia** refers to waking up at night by the urge to pass urine (Abrams et al 1984).
- f) **Immobility incontinence** refers to disease or disability that prevents sufferers gaining access to an appropriate place at an appropriate time to pass urine (Thomas & Dines, 1994).

Definition of Urinary Incontinence for this study

This study is not centred on any specific type of lower urinary tract symptoms. The aim of this study is to explore beliefs relating to urinary incontinence, with people who may have symptoms but have not sought help, and those who have sought help, within a specific religious group. Therefore, a broad definition was used in this study as follows:

'The complaint of any involuntary loss of urine' ... 'involuntary loss of urine that is a social or hygienic problem' (Abrams et al, 2002).

History of Urinary Incontinence

Urinary incontinence was first reported in the 11th century, by a Persian physician, Avicenna, who reported a connection between *'vaginal birth and a tear in the bladder which can result in incontinence of urine'* (Cron, 2003). Avicenna's final words in this subject were that, *'this is a condition that is incurable and remains so until death'* (Cron 2003). Early attempts at correction were simply to soak up the urine with a variety of methods, the majority of which used absorbent material. Attempts were made by many physicians to close fistulas. These include the Swiss physician Dr. Johann Fatio in 1675, Dr. Henry Levert in 1829, Dr. Montague Gosset 1834, and Dr. Peter Mettauer in 1836 (Zacharin, 2000). Dr. John Peter Mettauer in 1838 reported a

successful closure of a vesico-vaginal fistula using wire sutures, although the honour of this accomplishment is often given to Dr. James Marion Sims, 'the father of American gynaecology' (Todman, 2007) who improved the surgical techniques of fistula repair. To this day, many of his techniques remain the standard.

The first acknowledgement of urinary incontinence in nursing textbooks appeared from 1890 to 1899 (Phillips, 2004). Weeks-Shaw (1891) was the first trained nurse to publish a text on UI, based on advancing understanding: '*Incontinence of urine arises from weakness of the neck of the bladder, rendering it unable to restrain its contents.*' (Weeks-Shaw 1891).

Between 1900 and 1930, UI in general was not treated as a topic in its own right and was mainly ignored within the literature, although issues such as urinary retention, cystitis, cleansing and disinfecting catheters do appear (Watson, 1912). In 1922, the first mention of pelvic floor exercises appeared as a means of preventing urinary incontinence in women following childbirth by Dr. Joshua Davies (Moore, 1997). Harmer (1936) discussed nursing the incontinent patient in her textbook of 'The Principles and Practice of Nursing'. Harmer stresses the importance of using simple nursing measures prior to catheterisation, which consisted of regular toileting, reassuring and privacy as the main approaches to maintaining continence. Harmer (1936) further elaborated on complications that can arise from the incontinent person, such as skin deterioration and pressure sores. Assessment of the leakage, the amount, and odour of urine by health care professionals, as well as fluid intake and output were all charted in patient notes.

In 1940 Dr. Arnold Kegel, an obstetrician, contributed to the early work of Dr. Joshua Davies idea of using the pelvic floor muscles to improve urinary incontinence. Dr. Arnold Kegel contributed by adding a biofeedback device to pelvic floor exercises. The device is known as the Perineometer, which enables a woman to observe the strength and duration of her pelvic muscle contractions. Kegel reported in 1950 a high success rate or '*a complete relief of urinary stress incontinence by using the perineometer device*' (p. 791-792).

Psychological consequences of urinary incontinence were frequently reported. This included the depression and social isolation the individual can suffer. Price (1954) addressed the psychological affect of UI on the sufferer, and believed the only solution was the indwelling catheter. Newton (1966) was another author with a

successful outcome of a well-planned, long-term, and intensive treatment program. The success of this treatment is often measured by the degree to which the patient's symptoms are relieved. To this end, many studies have been conducted.

The first study was conducted by [Name] in 1980. This study was a randomized, controlled trial. The results showed that the treatment was effective in relieving symptoms. The study was published in the *Journal of Clinical Investigation* (1980, 65:123-130).

Between 1980 and 1990, a number of other studies were conducted. These studies were mostly ignored until the 1990s, when a meta-analysis was published. This meta-analysis found that the treatment was effective in relieving symptoms. The meta-analysis was published in the *Journal of Clinical Investigation* (1990, 65:123-130).

In 1990, Dr. Arnold Kegel, an expert in the field, conducted a study. This study was a randomized, controlled trial. The results showed that the treatment was effective in relieving symptoms. The study was published in the *Journal of Clinical Investigation* (1990, 65:123-130).

Psychological consequences of the treatment were also studied. This study was published in the *Journal of Clinical Investigation* (1990, 65:123-130).

special interest in promoting continence, in the hospital and care home environment. Newton's techniques are still practiced today, which include the use of large pads and regular toileting of the incontinent patient.

The early 1970s also saw a development of specialist nurses, physiotherapists and occupational therapists in the role of helping the incontinent patient (Casteldine, 1995). In 1998, the Royal College of Physicians published an audit focusing on the general lack of awareness of incontinence issues, and the unawareness of the treatments available to cure or manage the condition. The Department of Health in 2000 published a document 'Good Practice in Continence Care'. This document outlined the role of specialist continence nurses and physiotherapists. It was reported that rather than treating the underlying cause of UI, the focus should be centred on managing the problem.

Management of urinary incontinence

Treatment options today for urinary incontinence vary from the non-invasive to surgical procedures. The least invasive treatments will be considered first. Prior to any treatment carried out all patients will go through some tests to determine what type of UI they suffer from. The patient will maintain a bladder diary, recording the fluid intake and output with the number of incontinent episodes. This information is vital for the professional. Specialised tests include the post void residual measurement (PVR), which determines whether the patient has difficulty emptying the bladder. A stress test will be carried out to identify if the patient leaks urine when they increase abdominal pressure, when coughing, sneezing or laughing. Urodynamic testing measures the pressure in the bladder at rest and when filling, which helps identify the strength of the bladder muscle and health of the urinary sphincter (Abrams et al 2005).

Recognition of the financial burden

During the 1990s, the financial burden of UI was addressed. Anand (1990) stated that the expected cost of treatment for incontinence to the NHS would rise to 160% between 1980 and 2040. The real cost of urinary incontinence is not consistent as many sufferers will often self-manage. This management includes purchasing of sanitary pads, and extra bedding, clothing or absorbent products (Wilson et al 2001). A few comprehensive studies and limited data sets provide prevalence estimates in all groups. However, accurate prevalence rates are also limited due to the nature of incontinence as a hidden topic, which affects the analysis of the direct and indirect

costs of UI. Incontinence is not always diagnosed as a condition, so even where it has been reported to a doctor, it may not be recorded in a way that is retrievable for audit. Overall therefore, it has been difficult to measure the actual costs of this condition on health care services (Hu 1986; Biri et al 2006).

In one of the studies that had undertaken economic analysis, Hu (1986) identified the costs of incontinence from the perspective of the health care system and included the costs of assessment, diagnosis, rehabilitation and aids if finally necessary. This resulted in a sum of \$16.4 billion each year. Elia et al (2002) found a much higher rise of \$26.3 billion per year, suggesting that direct and indirect costs of urinary incontinence have increased and will increase annually (Stothers et al 2005). The cost consequences were also identified, including the treatment of skin irritation and urinary tract infections (Ouslander et al, 1990; O'Donnell et al, 1992). Tediosi et al (2000) found in their cross-sectional study in Italy, that the financial burden of incontinence was 173€ per year per patient. Similar findings were also reported by Hampel et al (2004) in an intensive review to understand the burden of UI in Europe. European countries included France, Germany, Italy, Spain and the UK. Birnbaum et al (2003) identified that the financial cost of treating urinary incontinence does not only stop there, but conditions such as this are related to other, often costly conditions. Birnbaum et al (2003) suggested that in the USA the lifetime cost for a sufferer was \$133,000 lifetime medical costs, compared to those who do not have this condition. If all direct costs were calculated, including assessment, diagnosis and treatment and self-management then these figures would be higher.

The Association for Continence Advice provided financial data on the costs of incontinence in the United Kingdom given by the Department of Health (1991). Fifty million pounds per annum was spent directly on pads and appliances, with an additional £18 million-worth of appliances being provided on prescription in England and Wales (DoH, 1991). A more recent study by Thakar and Stanton (2000), found significantly higher costs, reported at approximately £424 million per annum.

From the above section, it can be seen that the cost of urinary incontinence to the NHS and to the individual sufferer can be immense.

As stated previously in this chapter, urinary incontinence can happen to anyone at any age. Risk factors for developing UI have been extensively reviewed. In the following passage, I will draw attention to some of these risk factors.

costs of UI, incontinence is not well understood. However, it has been reported to a degree that it is a significant burden on the individual and society. Overall, therefore, it is a condition that is not well understood and its impact on health care systems is not well understood.

In one of the studies that have been conducted, the costs of incontinence from both direct and indirect costs of assessment, diagnosis, management, and care, have been estimated. In a study of 5141 men aged 65-74, the total cost of incontinence was estimated to be £252.3 million per year. This cost included the costs of assessment, diagnosis, management, and care, as well as the costs of lost productivity and the costs of social consequences. The study also found that the costs of incontinence have increased over time, and that the costs of social consequences were also significant.

Urinary tract infections (UTIs) are a common condition in the elderly, and they can be a significant burden on the individual and society. In a study of 1000 elderly patients, the costs of UTIs were estimated to be £1.2 million per year. This cost included the costs of assessment, diagnosis, management, and care, as well as the costs of lost productivity and the costs of social consequences.

European countries are increasingly aware of the burden of incontinence on the individual and society, and they are taking steps to reduce this burden. In the United Kingdom, the National Institute for Health Research (NIHR) is funding a programme of research into the costs of incontinence. This programme will include a study of the costs of incontinence in the United Kingdom, and a study of the costs of incontinence in other European countries. The study in the United Kingdom will include a study of the costs of incontinence in the United Kingdom, and a study of the costs of incontinence in other European countries.

The Association for Continence Advice (ACA) is a charity that provides information and support to people with incontinence. In the United Kingdom, the ACA is the leading charity in the field of incontinence. It provides information and support to people with incontinence, and it also provides information and support to health professionals. The ACA is also involved in research into the costs of incontinence. In the United Kingdom, the ACA is the leading charity in the field of incontinence. It provides information and support to people with incontinence, and it also provides information and support to health professionals. The ACA is also involved in research into the costs of incontinence.

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Risk factors

In addition to the factors described by Norton (1986), other authors have identified additional risk factors that may indicate a person's susceptibility to developing incontinence (Bump, 1993). There is obvious overlap between these and factors already described which by their nature are causative factors, and risk factors, such as vaginal childbirth, obesity, diabetes and asthma. Other risk factors identified from the adult literature include:

- Smoking
- Pregnancy
- Parity
- Body mass index (BMI)
- Ethnicity
- Previous surgery
- Family history of childhood bedwetting
- Lack of exercise (Herzog et al 1994; Bump and Norton 1998).

Knowledge about the epidemiology of urinary incontinence mainly derives from cross-sectional prevalence studies. There are limited longitudinal studies of incontinence incidence and remission. However, these studies have played an important role in the analysis of risk factors for developing lower urinary tract symptoms. Table two identifies some of the studies that have shown a positive link between the risk factors identified and leaking urine.

In addition to the factors described by Norton (1986), other authors have identified additional risk factors that may indicate a person's susceptibility to developing incontinence (Bump, 1983). There is obvious overlap between these and factors already described which by their nature are causative factors, and risk factors, such as vaginal childbirth, obesity, diabetes and asthma. Other risk factors identified from

the adult literature include:

- Smoking
- Pregnancy
- Parity
- Body mass index (BMI)
- Ethnicity
- Previous surgery
- Family history of childhood bedwetting
- Lack of exercise (Hartog et al 1984, Bump and Norton 1986).

Knowledge about the aetiology of urinary incontinence mainly derives from cross-sectional prevalence studies. There are limited longitudinal studies of incontinence incidence and remission. However, these studies have played an important role in the analysis of risk factors for developing lower urinary tract symptoms. Table two identifies some of the studies that have shown a positive link between the risk factors identified and leaking urine.

Table 2 Risk factors

Authors	Risk factors identified
Bump and McClish (1994)	Smoking
Wetle et al (1995)	COPD, asthma
Brown et al (1996)	Obesity
Diokno et al (1996)	Asthma, COPD
Nygaard and Lemke (1996)	Age
Thom et al (1997)	Obesity
Holtedahl and Hunskaar (1998)	Obesity, poor pelvic floor muscle, previous gynaecology surgery.
Brown et al (1999)	Obesity
Fultz et al (1999)	Obesity
Milsom et al (2000)	Race
Duong and Korn (2001)	Obesity
Graham and Mallett (2001)	Obesity
Sampselle et al (2002)	Increased BMI, Leiomyomd
Subak et al (2002)	Obesity
Sze et al (2002)	Age
Dallosso et al (2003)	Increased BMI, Smoking, Dietary habits.
Jackson et al (2004)	Race, estrogens use, arthritis, COPD, BMI, Diabetes, depression, old age.
Moorthy et al (2004)	Race
Waetjen et al (2007)	Age
Daneshgari et al (2008)	Age
Tennstedt et al (2008)	Age, Arthritis, Asthma, COPD, Race.

The above table provides a snap shot of some of the studies that identify risk factors, for a much more comprehensive list refer to table eight, nine and ten (appendix two, three and four).

Previous studies have shown a positive link between the risk factors and the development of lower urinary tract symptoms. Others have found no association between risk factors or the development of UI (Burgio et al 1991; Biri et al 2006). The evidence for these links is in most cases correlational and in some cases not statistically proven.

The following sections of this chapter will draw upon studies that examine the burden of urinary incontinence worldwide narrowing down to the UK and finally to the ethnic minority populations.

Table 2 Risk factors

Authors	
Bray and McGee (1982)	
Wells et al. (1985)	
Brown et al. (1987)	
Dickens et al. (1987)	
Wagstaff and James (1988)	
Tran et al. (1987)	
Hodgson and Hunt (1988)	
Brown et al. (1988)	
Fitz et al. (1989)	
Milson et al. (2000)	
Cheng and Kohn (2001)	
Graham and Miller (2001)	
Gompers et al. (2003)	
Stuck et al. (2003)	
Stee et al. (2003)	
Delbecq et al. (2003)	
Jackson et al. (2004)	
Morley et al. (2004)	
Weston et al. (2005)	
Ganapathy et al. (2006)	
Tennstedt et al. (2007)	

The above table provides a summary of the studies that have been conducted in the area of risk factors for a much more comprehensive review of the literature, see for example, the review by Wells et al. (1985). Previous studies have shown a significant relationship between risk factors and the development of lower urinary tract symptoms. The most common risk factors identified in the literature are age, duration of symptoms, and the presence of other medical conditions. Evidence for these links is strongest for age, which is consistently found to be statistically significant.

The following sections of the review discuss the evidence for the role of risk factors in the development of urinary incontinence. The review is organized into three main sections: (i) a summary of the evidence for the role of risk factors in the development of urinary incontinence, (ii) a discussion of the evidence for the role of risk factors in the development of urinary incontinence, and (iii) a discussion of the evidence for the role of risk factors in the development of urinary incontinence.

A search was performed using key words¹, to identify the studies on prevalence of UI by country, the reference list of the studies were searched too. Only those studies that were written in English were included. Appendix two (table eight) identifies prevalence studies worldwide, appendix three (table nine) provides details of studies within the UK, and appendix four (table ten) concentrates on those studies that have shown a link between ethnicity and urinary incontinence.

The authors identified (table eight) have published many well-designed studies, however not every study could be included as there is a large amount of literature. For example, the majority of the studies are USA based, and many have been conducted in the same year and in the same geographical area. Therefore, I chose the studies that surveyed mainly the largest sample and ones that were the only one that had been conducted in that country and with a specific group and date. Studies are identified under, authors, year of publication, sample size, study design, tool used, gender, age, type of UI, definition of UI, and summary of findings.

The following passages will however acknowledge studies that have not been placed in the tables.

¹ Key word search: urinary incontinence, worldwide, American, Black, White, Chinese, Hispanic, Asian, men, women. For example, the term incontinence was searched with each key word:

- Incontinence-urinary
- Incontinence-prevalence
- Incontinence-ethnic minority
- Incontinence-Muslim women

Database search: Biomed, BMJ, British Nursing Index, CINAHL, Google Scholar, JSTOR, Medline, Ovid, Web of Knowledge. A search was undertaken of relevant literature published between 1950 and 2008.

The search was modified to include only publications in English and those referring to humans. In addition, relevant current journals held in the University of Central Lancashire were searched. Although the first literature appeared in the 1890's in the nursing textbooks, this data was also considered. The search also revealed most of the studies in the field of urinary incontinence were conducted in the USA.

Obtained articles' reference list was also examined for any articles that may be of relevance to this study.

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The following passages will however acknowledge studies that have not been placed in the tables.

¹ Key word search: urinary incontinence, women, the American, Black, White, Chinese, Hispanic, Asian, race, women. For example, the term incontinence was searched with each key word: incontinence-urinary, incontinence-prevalence, incontinence-ethnic minority, incontinence-Asian women. Database search: EMBASE, BMD, British Nursing Index, CINAHL, Google Scholar, JSTOR, Medline, Ovid, Web of Knowledge. A search was undertaken of relevant literature published between 1950 and 2008. The search was modified to include only publications in English and those referring to human. In addition, relevant current journals held in the University of Central Lancashire were searched. Although the first literature appeared in the 1890's in the nursing textbooks, this data was also considered. The search also revealed most of the studies in the field of urinary incontinence were conducted in the USA. Obtained articles, reference list was also examined for any articles that may be of relevance to this study.

Worldwide studies

Prevalence of UI: worldwide

Appendix two (table 8) tabulates the twenty-five studies that were identified for this section. Some of these studies have taken a comparative cross-country approach. Thirteen studies were conducted in Europe, six in Asia. A further two in Australia, two in North America and two in South America. Nine studies used both men and women in the sample, although the majority of studies were conducted with female participants.

The following will be divided into subsections to provide an easier read.

Men versus women

These studies have identified that the prevalence of lower urinary tract symptoms (LUTs) in men is lower than that of women. Urge incontinence is the most prevalent type of lower tract symptoms men suffer from (Sandvik et al 1993). Campbell et al (1985) found men to suffer more from faecal incontinence than women. Men were more likely than women (2.6%) to suffer from mixed urinary symptoms. Mohide et al (1988) found that incontinence for men increased with age. The age range for men developing lower urinary tract symptoms was noticeable between the ages of 75-84 years.

Pinnock and Marshall (1997) agree with these findings and suggest common symptoms in men are those related to nocturia and frequency. Nocturia increased significantly with age, with 33% reporting symptoms in the age range of 65 and over. Incontinence in men increased with age and appeared to rise more steadily than it does in women (Sandvik et al 1993). Lee (2004) agreed with the above two studies, and found 25% of men over the age of 65 reported urinary symptoms.

Women

Studies relating to women with lower urinary tract symptoms (LUTs) are more common. Mohide et al (1988) found in their study in America that 68.5 % of the sample reported lower urinary tract symptoms. Ma (1997) found 34% of the sample in Hong Kong reported symptoms of LUTs, and Samuelsson et al (2000) reported 23.6% of women reported LUTs. The study in Australia by Pinnock and Marshall (1997) found a slightly higher rate at 39%, whereas one in Northern Ireland found an even higher prevalence of 43.9% (Dolan et al, 1999). Maggi et al (2001), who studied Italian women, found 21.6% reported LUTs, whereas Lee (2004) identified 55%.

It is evident that prevalence rates have increased in recent years. These can be related to many factors, which are discussed later.

Prevalence in women by the type of UI

According to Cardozo and Cutner (1993), 15-30% of women in all range groups are affected, although women can suffer from any of the types of urinary incontinence. According to Tapp et al (1988), stress incontinence has traditionally been associated with pregnancy, vaginal delivery, previous gynaecological surgery, and menopause, which explains why stress UI is more prevalent in women. From the studies above Campbell et al (1985), reported that women had a higher incidence rate of stress UI. Grimby et al (1993) found 28.3% of the sample reported stress urinary incontinence, 40% reported urge urinary symptoms, and 31.7% reported mixed urinary symptoms. A larger study by Lapitan and Chyeon (2001) in Asia found the prevalence of OAB in the population studied was 51.4%. The most common symptom reported was urgency at 65.4% followed by frequency 55.4% and 21.4% reported urge incontinence. Espino et al (2003) found 51.9% of women in their study reported stress UI and 74.9% reported symptoms of urge UI. Hunskaar et al (2004) conducted a large study consisting of 29 500 women across Europe. It was found that women in the United Kingdom were more likely to report symptoms of stress UI (41%), than in the other countries, women in France reported higher symptoms of urge incontinence (27%), and women in Germany were more likely to report higher symptoms of mixed UI at 38%. Spain was the only country in this study to report lower levels of any type of lower tract symptoms. Pang et al (2005) found reports of 13% of women developed symptoms of stress UI and 15.5% reported symptoms of urge UI, a study conducted in Hong Kong. Biri et al (2006) found 16.1% of women in their study in Turkey reported stress UI.

Age and childbirth

Another recurrent theme is related to age. The older the woman the more likely it seems to be that she will develop UI (Mohide et al, 1988; Biri et al, 2006). Foldspang et al (1999) found that for women between the ages of 20-29 the prevalence was 9.6%, whereas in women between the ages of 50-59 the prevalence increased dramatically up to 32.4%. Melville et al (2005) found the prevalence of LUTs increased even further in women between the ages 80 to 90 years, reported at 33%. Three studies reported a positive link between lower urinary tract symptoms and vaginal childbirth (Thomas et al, 1980; Foldspang et al, 1992; Rortveit et al, 2003).

It is evident that prevalence rates have increased in the last 20 years, but this is related to many factors, which are discussed below.

Prevalence in women is the high (1.5-10%) in the last 20 years. According to Gordon and Chinn (1993), 17.2% of women in the United States reported, although women can suffer from the condition. According to Tapp et al. (1993), 10% of women in the United States reported, which explains why stress UI is the most common form of UI. Campbell et al. (1993) reported that 10% of women in the United States reported, which explains why stress UI is the most common form of UI. Ghiny et al. (1993) found 23.7% of women in the United States reported, which explains why stress UI is the most common form of UI. 40% reported urge urinary incontinence, and 27.3% reported stress urinary incontinence. A larger study by Laidan and O'Leary (1993) found that 10% of women in the United States reported, which explains why stress UI is the most common form of UI. The population studied was 24.4% of women in the United States reported, which explains why stress UI is the most common form of UI. Incontinence. Basso et al. (1993) found that 10% of women in the United States reported, which explains why stress UI is the most common form of UI. stress UI and 14.9% reported urge urinary incontinence. A large study consisting of 20.2% of women in the United States reported, which explains why stress UI is the most common form of UI. the United States, women more than 50 years of age reported, which explains why stress UI is the most common form of UI. the other countries, women reported, which explains why stress UI is the most common form of UI. (27%) and women in Germany reported, which explains why stress UI is the most common form of UI. UI at 33%. Spain was the only country where the prevalence of stress UI was higher than 30%. of lower tract symptoms. In Spain, 10% of women reported, which explains why stress UI is the most common form of UI. developed symptoms of stress UI and 14.9% reported urge urinary incontinence. conducted in Hong Kong, 10% of women reported, which explains why stress UI is the most common form of UI. Turkey reported stress UI.

Age and childbirth

Another recurrent theme is related to the age of the women. It seems to be that the risk of stress UI increases with age. et al. (1993) found that for women, the risk of stress UI was 9.3%, whereas in women between the ages of 10-19, the risk was dramatically up to 33.4%. In the last 20 years, the prevalence of stress UI increased even further in women between the ages of 10-19, which was 33.4%. Three studies reported a similar trend, which was that the prevalence of stress UI increased with age. et al. (1993) found that the prevalence of stress UI was 9.3%, whereas in women between the ages of 10-19, the risk was dramatically up to 33.4%. In the last 20 years, the prevalence of stress UI increased even further in women between the ages of 10-19, which was 33.4%.

The prevalence increased even further in women who had given birth to four or more children.

Conclusion from the above studies

The above studies of prevalence by country have shown that urinary incontinence is more common in women, being reported by 8.6% of women aged 16-64 years (Thomas et al, 1980) and objectively demonstrated in 12.1-25% of women aged 46-85 years, increasing with age (Molander, 1993). Walker (1987) suggests that while incontinence is more prevalent among the elderly, its occurrence is significant across all age groups (Mohide et al 1988; Foldspang et al 1992). UI prevalence varies between countries, but there is evidence that similar levels of UI have a similar impact on daily activities. An accurate estimate of urinary incontinence for all ages is unavailable. Almost all studies confirm that prevalence increases with age and childbirth is a confounding factor (Swithinbank et al, 1999; Lapitan & Chyeon, 2001; Maggi et al, 2001; Espino et al, 2003; Melville et al, 2005; Biri et al, 2006).

This section has identified that only a small number of research studies in this area were conducted in the UK, with the majority in America. As this study is UK based, an overview of the UK research studies is given in the following section

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Conclusion from the above studies

The above studies of prevalence by country have shown that urinary incontinence is more common in women, being reported by 8.6% of women aged 18-64 years (Thomas et al, 1980) and objectively demonstrated in 12.1-25% of women aged 48-65 years, increasing with age (Molander, 1983). Walker (1987) suggests that while incontinence is more prevalent among the elderly, its occurrence is significant across all age groups (Molander et al, 1988; Feldberg et al, 1992). UI prevalence varies between countries, but there is evidence that similar levels of UI have a similar impact on daily activities. An accurate estimate of urinary incontinence for all ages is unavailable. Almost all studies confirm that prevalence increases with age and childbirth is a confounding factor (Swilbank et al, 1999; Caplan & Cline, 2001; Maggi et al, 2001; Espino et al, 2003; Melville et al, 2005; Bitt et al, 2006).

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UK studies

Prevalence of UI in the UK

Appendix three (table nine) draws attention to the prevalence studies conducted in the UK. The identified authors in this table have also published many studies on urinary incontinence, again I have considered those studies that applied the largest sample size, and that were conducted in different geographical areas of the UK. Studies were characterised under similar headings, authors, year of publication, sample size, tool used, gender, age, type of UI, definition of UI, and summary of findings (see table nine)². Similarly the following passage will include those studies that are not provided in table nine.

Identifying the exact prevalence of UI in the UK is difficult due to the definitions of incontinence being different or not included in the studies (Mohide, 1992; Williams et al, 1995; Button et al, 1998). However, an overview of the prevalence as found is presented below. Twelve studies were identified. Eight of the twelve studies included both men and women in the sample, although the majority of studies focused predominantly on female participants.

Men versus women in the UK

As noted in the previous section, prevalence of UI in men has generally been reported to be lower than that for women. This is also similar to those studies conducted in the UK (Perry et al 2000; Roe and Doll 2000). A study by Thomas et al (1980) however found that men were more likely to suffer from regular and occasional episodes of incontinence, not found in studies conducted in America.

² Search strategy: urinary incontinence, United Kingdom, Black, White, Chinese, Asian, men, women. For example, the term incontinence was searched with each key word:

Incontinence-urinary

Incontinence-prevalence

Incontinence-ethnic minority

Incontinence-Muslim women

Database search: Biomed, BMJ, British Nursing Index, CINAHL, Google Scholar, JSTOR, Medline, Ovid, Web of Knowledge. A search was undertaken of relevant literature published between 1950 and 2008.

The search was modified to include only publications in English and those referring to humans. In addition, relevant current journals held in the University of Central Lancashire were searched. Although the first literature appeared in the 1890's in the nursing textbooks, this data was also considered.

Obtained articles' reference list was also examined for any articles that may be of relevance to this study.

The prevalence rates for developing certain types of UI remain similar to those found worldwide (Yarnell and Leger 1979; O'Brien et al 1991; Perry et al 2000; Stoddart et al 2001).

The higher incidence of developing UI amongst women worldwide is similar to women in the UK compared to men (Thomas et al 1980; Harrison and Memel 1994; Swithinbank et al 1999; Perry et al 2000; Roe and Doll 2000).

Types of UI

A higher prevalence of stress UI in women was evident from the above studies. Jolleys (1988) found 16% of women reported symptoms of stress UI regularly, although a further 81% reported symptoms of stress UI to occur occasionally. Jolleys (1988) does not use a definition for stress UI, however it was evident from the results that stress UI is what Jolleys explored with the sample, for example, have they leaked 'on laughing, coughing, sneezing, exercising or climbing'. Stress UI was reported in 55% of women, urge UI in 10%, mixed in 31% and other in 4% of women (O'Brien et al 1991).

Harrison and Memel (1994) found 8% of women reported urge UI, 46% reported stress UI, mixed UI was reported by 43% of the sample. Jolleys (1989) also found a higher prevalence of urge UI reported at 73% of the sample followed by 24% of women reporting stress UI. Stoddart et al (2001) found symptoms of stress UI to be reported in 48% of the sample and a further 53% of women reported symptoms urge UI. Swithinbank et al (1999) study found stress UI reported at 60%, and urge UI by 46% of women. Although Swithinbank et al (1999) found urgency to be the most common reported LUTs by 61% of women, which significantly increased with age.

It is evident from the above studies that women in the UK are more likely to have symptoms of stress UI, followed by urge UI.

Age, childbirth and other medical conditions

Increased age is one of the well-known factors for developing LUTs (Stoddart et al 2001). Both men and women in the age range of 75 years and over, experienced an increased rate of UI reported up to 21% (Yarnell and Leger, 1979). O'Brien et al (1991) found the prevalence of stress UI decreased with age, for example in people between the ages of 35 to 54, stress UI was reported by 65% of participants, 40% by people over the age of 65 years, and 20% in people over the age of 85 years. Urge

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Harrison and Menzel (1994) found 5% of women reported urge UI, 48% reported stress UI, mixed UI was reported by 43% of the sample. Jolley (1988) also found a higher prevalence of urge UI reported at 75% of the sample followed by 24% of women reporting stress UI. Stoddart et al (2001) found symptoms of stress UI to be reported in 48% of the sample and a further 53% of women reported symptoms urge UI. Swinbank et al (1999) study found stress UI reported at 80%, and urge UI by 48% of women. Although Swinbank et al (1999) found urgency to be the most common reported LUTS by 61% of women, which significantly increased with age.

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UI and mixed UI showed a reversed affect increasing therefore with age in women (O'Brien et al 1991). Swithinbank et al (1999) found that in women between the ages of 19 to 39 years, 55% reported symptoms of LUTs, ages 40 to 59 years old reported by 76%, over the age of 80 years, 76% reported LUTs (Swithbank et al 1999). Thomas et al (1980) found UI to be more prevalent in women between the ages of 25-64 years. However, Jolleys (1988) found women in the age ranges 35-44 reported at 46%, with a further increased rate of 60% in the age range of 45 to 54 years. Perry et al (2000) found the prevalence of UI in women peaked in the early 50s, declining in the 60s and rising again in the 75 year olds and older. There was a positive link between increased LUTs and age. O'Brien et al (1991) found 18% of women over the age of 75 years experienced regular UI symptoms, as well as 15.4% of men in this age group.

Yarnell and Leger (1979) found UI increased significantly for men over 80 years old ranging from 19% to 25.4% (Thomas et al 1980). Brocklehurst (1993) found 8.8% of men reported symptoms of UI, with an increase of symptoms by the age 60 years and over reported at 16.3%. Stoddart et al (2001) further found for men 80 years old and over the prevalence increased up to 34%. Old age was identified as a factor for developing LUTs (Brocklehurst 1993). For men then LUTs steadily increased with age.

Both men and women believed the cause of their UI was due to medical conditions. Findings suggest a relationship between UI and a history of related conditions (Yarnell and Leger, 1979). Yarnell and Leger (1979) found that 62.1% of women related their UI to other medical conditions verses 44% of men. Medical conditions included cerebrovascular disease, prostatic hypertrophy, uterovaginal prolapse, geriatric admissions and medication (Yarnell and Leger, 1979). Jolleys (1989) found that 66% of women believed their UI was due to previous gynaecological surgery.

Childbirth was another common factor associated with UI. Jolleys (1989) found UI increased with parity, being 42% after one birth, 48% after two, 53% after three, and 56% in those with four pregnancies. Twenty six percent of women believed childbirth was the cause of their UI (Brocklehurst 1993).

Thomas et al (1980) stated urinary incontinence was less commonly reported by nulliparous than parous women at all ages, except in the age group of 45-54. Onset of UI was developed during the first pregnancy by 27% of women (Jolleys 1989).

Women who had four or more children were most likely to report regular incontinence. One hundred and six parous women were incontinent compared to 21 nulliparous women (Harrison and Memel, 1994). Incontinence was positively related to parity (Harrison and Memel, 1994), but no evidence was found of the association with the mode of delivery, gynaecological surgery, and age. McGrother et al (2003) found that women, after the menopause, showed a decline in the symptoms of LUTs, in contrast to men in this age range.

Conclusions from the studies in the UK

From the above studies, it can be seen that the prevalence of UI in the UK varies between 9% to a high of 75% depending on the type and severity. These studies suggest that UI in the UK is a common condition especially among the older populations. The association of UI with age, sex and type of UI was generally anticipated. Little comparable data has been published about men, although the prevalence reported in the studies suggests that it is a serious health problem for older men. The variation in outcomes across the included studies may be due to differences in definitions used, sample, response rate, age, gender, and availability of services, knowledge, and other factors.

More than 12 definitions were used in the above studies. Studies that used broad definitions of UI had a higher prevalence rate than those using the ICS definitions. Another important factor is the type of method used, questionnaires or interviews, and the manner in which the questions about UI were asked, verbally or non-verbally. Following a systematic review of studies of the prevalence of urinary incontinence, Mohide (1992) concluded that prevalence rates vary depending on the definitions of incontinence, samples, methods of data collection and settings used, and that comparisons of studies were not possible.

For example, Burgio et al (1991), Cutler et al (1992), Harrison and Memel (1994) asked participants very broad questions, which then inevitably increased prevalence rates up to 52% and 60% in women, suggesting that two in every three women had at some point experienced involuntary urine loss. On the other hand, the prevalence study by Thomas et al (1980) found only 8.5% of women reported symptoms of UI, which was defined as one or two episodes of leakage per month. Despite the number of new prevalence studies, none have been as large as that undertaken by Thomas et al, (1980) in the United Kingdom. This study therefore continues to be the most quoted by authors.

Norton (1996) states it is likely that about three million people are regularly incontinent in the UK, a prevalence of around 40 per 1000 adults. Figures produced by the Royal College of Physicians (1995) show an increase in the number of people with incontinence, but this may be evidence of more people coming forward for help or admitting the problem.

Urinary incontinence remains a worldwide problem affecting women and men of all ages and across different cultures and ethnicity. Prevalence rate data has been primarily obtained from studying the White populations. There is limited data on the prevalence rates in other ethnic minority populations. The next section of this chapter will therefore concentrate on the reported prevalence studies amongst different racial groups.

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Urinary incontinence remains a worldwide problem affecting women and men of all ages and across different cultures and ethnicity. Prevalence rate data has been primarily obtained from studying the White population. There is limited data on the prevalence rates in other ethnic minority populations. The next section of this chapter will therefore concentrate on the reported prevalence studies amongst different racial groups.

Race as a risk factor

Prevalence of UI in the ethnic minority groups

Appendix four (table ten) draws attention to those studies that have considered 'race' as a risk factor for developing UI. Many definitions of ethnic, race or ethnic groups have been applied to previous studies, the Oxford dictionary defines 'ethnic' '*of race or relating to classification of humans into social or cultural groups*' (pg 257) whereas 'race' is defined as '*a group of people of common ancestry with distinguishing physical features*' (pg 606). Both these terms are describing a group of people that are known to have similar features and beliefs as well as the obvious features as skin colour, that are different from the host populations.

Groupings of the ethnic minorities have caused conflicting results as their definitions in various countries have varied. For example, in the USA, the term 'Asian' refers to people predominantly from East Asian or Southeast Asian heritage, which includes Chinese. However, in the United Kingdom, Asian usually refers only to South Asians; Indians, Pakistani, Bangladeshis, Kashmiris and Sri Lankan's, whereas Chinese or Vietnamese are referred to as oriental in the UK, and are usually not included in the term.

There has been little published information about UI in women or men of ethnic and racial minority groups. This information is important because it could help health care professionals to anticipate need in minority groups.

Risk factors for and conditions of UI differ significantly between ethnic groups (Bump 1993). Racial differences and prevalence of incontinence subtypes may have importance for the diagnosis and prevention of UI. More recent research (Duong & Korn 2001; Graham & Mallett 2001; Novielli et al 2003; Song et al 2005; Teo et al 2005) conducted in the field of UI and women has explored whether ethnicity is a predominant risk factor³. There is conflicting evidence that ethnicity influences the overall risk of incontinence. The following section explores this topic. Again, it is

³ Search strategy: urinary incontinence, Black, White, Chinese, Hispanic, African. For example, the term incontinence was searched with each ethnic group.

Database search: Biomed, BMJ, British Nursing Index, CINAHL, Google Scholar, Ovid. A search was undertaken of relevant literature published between 1950 and 2008.

The search was modified to include only publications in English and those referring to humans. In addition, relevant current journals held in the University of Central Lancashire were searched.

Obtained articles' references list was also examined for any articles that may be of relevance to this study.

worth noting that the majority of prevalence studies in this area have been conducted in America.

Types of UI

The prevalence of stress UI is thought to be significantly lower in black women than in White women. Bump (1993) examined 200 consecutive patients. Of the 54 black women in this group, 27% were diagnosed with stress UI compared with 61% of White women. Similarly, Peacock et al (1994) reviewed 159 black women and found the prevalence of stress UI to be 28%. Sze et al (2002) in their study found 42% of White women reported stress UI compared to black or Hispanic women (39% and 24%). Similarly Jackson et al (2004) found 73% of White women reported symptoms of stress UI compared to 27% of black women. Therefore, from these studies it can be seen that women from the White population appear to be more likely than black or Hispanic women to suffer from stress UI (Waetjen et al 2007).

Thom et al (2006) found comparable results. Asian-American women reported lower levels of stress, while White and Hispanic women reported relatively high levels. Twice the risk of developing stress UI was noted in the White population than Asian-American or black women. A recent study by Tennstedt et al (2008) reported similar findings, suggesting stress UI was highest amongst White women than black or Hispanic women (35.4% vs. 9.4% vs. 14.5%).

Although this suggests the White population appears to be more likely to suffer from stress UI, other studies have found different results. For example a study conducted by Mattox and Bhatia (1996) found a higher proportion of Hispanic women (41%), reported symptoms of stress UI than White women (26%). Stress UI was also reported higher in African-American women (34%) than in White women (25%). Duong and Korn (2001) found similar results, 69% of Hispanic women reported stress UI compared to African-American women (48%) and 15% in White women. Daneshgari et al (2008) also found lower reports of stress UI in White women compared to Hispanic women.

The White population also appears to show higher prevalence of urge UI. Mattox and Bhatia (1996) found in their study urge UI was reported higher in White women than Hispanic women, (18% vs. 9%). Similar findings by Sze et al (2002) showed White women were more likely to report higher prevalence rates of urge UI (19%) compared to 16% black and 16% Hispanic women. In a study of urinary incontinence

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The prevalence of stress UI is thought to be significantly lower in black women than in White women. Bump (1983) examined 500 consecutive patients. Of the 54 black women in this group, 27% were diagnosed with stress UI compared with 61% of White women. Similarly, Prescott et al (1994) reviewed 159 black women and found the prevalence of stress UI to be 23% (size et al (2002) in their study found 42% of White women reported stress UI compared to black or Hispanic women (38% and 24%). Similarly, Jackson et al (2004) found 73% of White women reported symptoms of stress UI compared to 27% of black women. Therefore, from these studies it can be seen that women from the White population appear to be more likely than black or Hispanic women to suffer from stress UI (Weaston et al 2007).

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The White population also appears to show higher prevalence of urge UI. Mattox and Britta (1998) found in their study urge UI was reported higher in White women than Hispanic women (18% vs. 9%). Similar findings by Size et al (2002) showed White women were more likely to report higher prevalence rates of urge UI (19%) compared to 16% black and 18% Hispanic women. In a study of urinary incontinence

in the elderly, Jackson et al (2004) report 64% of White women reported weekly urge UI, compared to 55% of black women. Tennstedt et al's (2008) findings also suggest that urge UI is higher amongst White women than black or Hispanic women (13.4% vs. 3.3% vs. 10.8%). Although a higher prevalence of overall UI (all types) is reported in the White population, in a study conducted by Thom et al (2006) found black women had the highest prevalence of urge UI specifically.

Peacock et al (1994) reported on the physiological differences between black women and White women. It was found that black women had a 21% greater urethral volume, and the mean Kegel urethral closure pressure was 29% in black women, suggesting black women had a higher urethral closure pressure than White women. This is consistent with the fact that black women have a higher appendicular skeletal mass than White women (Gasperino et al 1995). Higher urethral closure pressure in black women suggests that sphincter function might play a greater role than support in maintaining continence during stress. Graham and Mallett (2001) also found African-American women had higher maximum urethral pressure than White women.

The findings converge with those of others (Bump 1993; Fultz et al 1999), with respect to decreased risk in black women and are consistent with higher levels of pelvic floor strength as reported by Howard et al (2000). The White population appears to be a significant predictor of stress UI, but the African-American population is associated with detrusor instability or urge UI due to physiological difference. However, more research is needed to determine this.

Conclusions from the above studies

The assumption of race/ethnicity as a risk factor for the prevalence and incidence of lower urinary tract symptoms and disorders has been studied and questioned by many (Bump 1993). The question remains whether ethnicity is positively linked to developing certain lower urinary tract symptoms. From the above comparison, notable differences do appear to exist between racial groups. Overall it can be assumed that most studies found that African-American and Hispanic women had the lowest prevalence of stress UI, while White women had the highest (Sampselle et al 2002; Waetjen et al 2007). Conclusions have been drawn that the development of LUTs could be related to physiological and body composition.

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Urinary incontinence in the Asian communities in the UK

Asian Communities and UI

Many of the studies that have been conducted in the Asian communities in the UK in regards to UI have concentrated on the educational needs and promoting UI within this group. Therefore, a prevalence table could not be provided. However, from the studies that have been conducted it appears that Asian communities are less likely to discuss stigmatising conditions, a reluctance which can be attributed to cultural factors, namely a lack of willingness to report what is considered a sensitive and private matter.

Although studies have reported a positive link between UI and parity, can it be assumed that the Asian communities are more likely to develop UI due to the larger numbers of parities? Pregnancy is another contributing factor for developing UI. Both Scott (1999) and Haggart (1995) have established that women from this ethnic minority group needs to be educated from the early stages of pregnancy as they are at particular risk of developing incontinence problems due to the number of parities. Carlisle (1998) further found many women from this ethnic minority group have four or more children and therefore had an increased risk of developing stress incontinence (Bump 1993; Wilkinson and Williamson 1995; Scott 1999). Wilkinson & Williamson (1995) found Pakistani Muslim women were more likely to develop UI due to the large numbers of parities and low levels of attendance at antenatal classes. As Haggart (1994) found, it was culturally unacceptable to talk about sexual relationships and contraception issues which restricted many attending antenatal classes. The true prevalence of UI is difficult to ascertain, especially in the hard to reach groups such as the Asian communities.

A small number of studies have examined cultural or ethnic influences on UI. Chaliha & Stanton (1999) found that Muslim women reported more sexual and religious restrictions related to their UI than Hindus, Jews, Buddhists or Christians. Wilkinson (2001) concluded that Pakistani women with incontinence have distinct cultural, language and religious characteristics that need to be understood by health professionals if they are to provide effective treatment/services. These women felt that health care professionals were not interested in their problems and did not provide adequate support, thereby restricting their ability to seek further services. Wilkinson (2001) also reported that these women experienced low self-esteem and feeling 'sinful', related to their religious expectations. Despite the lower prevalence of

Urinary incontinence is the leading health problem in the elderly population.

Asian Communities with Urinary Incontinence

Many of the studies that have been conducted in the Asian community have been cross-sectional and have not taken into account the possibility of recall bias. In addition, the majority of the studies have been conducted in the elderly population, and have not taken into account the possibility of recall bias. In addition, the majority of the studies have been conducted in the elderly population, and have not taken into account the possibility of recall bias.

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UI in certain ethnic groups, there may be ethnic differences on the affect of UI on daily life.

A much more recent study by Doshani et al (2007) on South Asian Indian women found similar views. Normalisation was a key barrier that restricted women seeking health care. Coping strategies that many of these women apply were similar to those considered by White women, which generally consist of sanitary pads, fluid restriction and restricting social movements. The most significant finding in this study was related to difficulties encountered when discussing stigmatising conditions with GPs. Women in this study felt that GPs dismissed their concerns (Doshani et al 2007).

Overall Conclusions on the prevalence studies

The above sections, page 36 to 48 have drawn on previous studies on urinary incontinence to provide a concise overview of the type of studies conducted. Twenty-five studies were identified from literature worldwide including thirteen from Europe, six from Asia, two from Australia, two from North America and two from South America (appendix two). The next section focuses on the prevalence figures/studies within the UK; twelve studies were included in this section (appendix three). As the focus of this study was on the 'racial or ethnic aspects of UI', the following section therefore drew on those studies that considered whether 'race' was a risk factor for developing urinary incontinence (appendix four).

The review includes only those studies that have concentrated on urinary incontinence and does not consider faecal incontinence. The review included discussion around the prevalence, incidence, and racial and ethnic differences. Risk factors were identified in these epidemiological studies, which have allowed areas for further research to be conducted. Urinary incontinence is a socially belittling condition and these studies have been important to identify the impact of UI on the sufferer's life, the prevalence and incidence rates within groups and in different racial groups. The majority of these studies have generally taken an observational cross-control approach (Foldspang et al 1992; Rortveit et al 2001) or a cohort approach (Seim et al 1996), and therefore there are limitations regarding conclusions about causality. Longitudinal studies are more likely to be valid (Campbell et al 1985; Grimby et al 1993; Dolan et al 1999; Moller et al 2000; Samuelsson et al 2000).

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One of the major problems identified through this review was the different definitions and measurements, which contributed to the wide range of reported prevalence estimates (pg 12-14). For example, Holtedah and Hunskaar (1998) calculated the prevalence estimates using different definitions of UI for the same sample of 50 to 70 year old women. The prevalence of any self-reported leakage was 47%. Self-reported regular UI with or without objective demonstration was found for 31% of women, regular incontinence according to the former full ICS definition for 19%. Another example is the study by Swithinbank et al (1999) who found a much higher figure using the ICS definition, reported at 30 to 69% and 30%. Appendix two and three illustrate definitions the author(s) have used in their studies. Out of these 38 studies, 13 studies used the ICS definition of urinary incontinence, '*an involuntary loss of urine that is objectively demonstrable and a social or hygienic problem*' (Abrams et al 2002), nine studies did not provide any definite definition and 16 used their own definitions. Drawing prevalence and conclusions from studies that have used wide variations in the definitions applied can be difficult and for such reasons Abrams et al (2002) proposed that all studies relating to faecal or urinary incontinence should consider the definitions suggested by the ICS.

Prevalence figures have differed in the use of different settings and different samples, such as the elderly populations (Campbell et al 1985; Maggi et al 2001; Espino et al 2003), multiparous (Moller et al 2000; Rortveit et al 2001) and nulliparous women (Hagglund et al 1999). However, even across population-based studies using comparable definitions of incontinence, prevalence estimates vary (Herzog and Fultz 1990; Thom 1998; Hunskaar et al 2000). Different settings and the sample are more likely to influence prevalence as well as severity. This is another cause of concern with the review as studies have used different severity levels and periods for dealing with UI. According to Kawauchi et al (2001) urinary incontinence often starts slowly, usually without the sufferer noticing it as a problem, before it becomes fully establish. Therefore, the figures can vary depending on where the samples are recruited from, i.e. community, or clinic settings.

Prevalence and incidence can also vary due to the 'taboo' surrounding this condition. Fultz and Herzog (1993) identified that low response rates may further bias prevalence estimates. People who suffer from incontinence may not admit to the condition because of embarrassment or related difficulties, i.e. psychological, emotional, physical etc. The interpretation and awareness of symptoms of UI, as well as the tendency to report symptoms may also vary between sub-groups of

One of the major problems in the study of prevalence is the lack of a clear definition of the condition being studied. This is particularly true for mental health conditions, where the boundaries between normal and pathological are often blurred. For example, the DSM-IV defines major depressive disorder as a mood disorder characterized by a persistent feeling of sadness and loss of interest, but the criteria are often subjective and difficult to apply in practice. This lack of clarity can lead to inconsistent prevalence estimates across different studies.

Another major problem is the issue of recall bias. Prevalence studies often rely on self-reported data, where individuals may not accurately remember when they started experiencing symptoms. This is particularly true for conditions that develop gradually or have intermittent symptoms. For example, a person might not realize they have a chronic condition until it becomes severe, leading to an underestimation of prevalence.

The third major problem is the issue of sampling bias. Prevalence studies often use convenience samples, such as patients in a clinic or members of a community group. These samples may not be representative of the general population, leading to biased prevalence estimates. For example, a study of mental health prevalence conducted in a psychiatric hospital would likely overestimate the prevalence of mental health conditions compared to a study conducted in a general community.

Finally, the fourth major problem is the issue of comorbidity. Many mental health conditions co-occur, and this can make it difficult to accurately estimate the prevalence of each condition. For example, a person might have both major depressive disorder and anxiety disorder, and this can lead to an overestimation of the prevalence of each condition if they are not properly accounted for in the study design.

women. Most epidemiological studies of UI have been conducted in all Caucasian populations, understanding and reporting the prevalence of UI in ethnic groups has generally been lacking. This may be due to the country in which the study was conducted. For example, the majority of research in this field is based in USA, where the definition of 'Asian' is different to that within the UK (pg 30). Therefore, caution should be exercised when comparing prevalence figures.

The review has shown that urinary incontinence is a common problem, affecting between 2% and 10% of men and 8% and 25% of women. Prevalence studies of urinary incontinence in the United Kingdom revealed that between 12% and 50% of people with urinary incontinence did not consult their doctors about their complaint (Jolleys, 1988; O'Brien et al, 1991; Brocklehurst, 1993; Harrison & Memel, 1994). These and other studies have also shown that people are in fact reluctant to tell anyone about their problem. It is evident from this review, and seems generally to be accepted, that incontinence is a common problem affecting both sexes across the whole age spectrum, its prevalence being greatest in women and elderly people.

The impact of UI on the individual is repeatedly mentioned in previous research as a condition which negatively affects the sufferer. The following section will draw on some of these factors.

Experiences and impact of Urinary Incontinence

Urinary incontinence is a common condition-affecting people of all ages from all social and cultural backgrounds (Horsfield 1986). It is not a classified illness, but a symptom with many causes (DoH 2000). Whilst the physical affects may not be clinically life threatening, the symptoms can have a devastating affect on the quality of life of sufferers, their families and friends (Horsfield 1986; Helman 2001). Grimby et al (1993) comments on the affect of UI, and states relationships can be reduced to an endless round of washing and changing, which can become an intolerable burden. Feelings of anger, guilt and frustration are common themes that are frequently expressed both by those with the problem and by their carers (Burgio et al 1991).

Although UI can negatively affect the sufferer there are studies that have found UI to create great inconvenience. The majority of sufferers do report negative effects and increased personal costs of their condition, often in terms of distress, embarrassment

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and inconvenience (Ouslander & Abelson, 1990; Lagro-Janssen et al, 1992; Brocklehurst, 1993). The degree of problems experienced does not necessarily correlate with the clinical severity of UI. Severity of incontinence can be defined based on frequency, typical quantity of urine lost or a combination of these factors (Sandvik et al 1993; Hannestad et al 2000; Sampsel et al 2002; Sandvik et al 2000). The impact of UI can be measured in terms of 'bothersomeness' or actions taken to ameliorate the incontinence, such as wearing pads, reducing activities, or seeking medical attention. Not surprisingly, women with more severe UI tend to report a greater impact (Miller et al 2000; Burgio et al 1991). Several scales have been developed to measure UI impact (Wyman et al 1990; Kelleher et al 1997; Wagner et al 1996; Yu, 1987) but have been used mostly in clinical trials.

For many people, incontinence is a source of embarrassment or shame rather than a signal to them that they should seek medical help. The dysfunction is seen mainly in terms of its social consequences rather than as a symptom of a possible underlying illness or disease process. Personal and social attitudes towards incontinence are not, however, the only factors that account for the under reporting of this widespread health problem. Many experience anxiety, sexual difficulties, impaired social and mental well-being and are less likely to undertake a wide range of activities (Norton 1982; Norton et al 1988; Wyman et al 1987; Bjurbrant-birgersson et al 1993; Fillingham and Douglas, 2004).

Hunskar & Vinsnes (1992) have found that while incontinence has an adverse effect upon quality of life, the extent depends on the type of incontinence and age. Wyman et al (1987) state mixed UI is more distressing, as individuals are unable to determine when they may leak, causing more distress. Coyne et al (2003) in their study on the impact of stress UI, urge UI and mixed UI, found individuals with symptoms of urge UI reported significantly higher levels of distress than those who suffered stress UI or mixed UI (Vinsnes and Hunskar, 1992; van der Vaart et al 2002). Depending on the type of lower urinary tract symptoms the individual suffers, the degree of distress will also differ.

Reymert & Hunskar (1994) found that 36% of the peri-menopausal women in their study had told no one and 28% had told only their husbands or a friend. The most common reason given in all these studies for not seeking help was that urinary incontinence was not a problem for the individual. However, the next most frequently given reasons relate more to the public's lack of understanding of the continence. People thought that urinary incontinence was 'normal for their age' and 'usual female

and incontinence (Gustander & Aabelson, 1999; Lago-Janssen et al., 1993; Brockhurst, 1993). The degree of problems experienced does not necessarily correlate with the clinical severity of UI. Severity of incontinence can be defined based on frequency, typical quantity of urine lost or a combination of these factors (Sandvik et al., 1995; Hannestad et al., 2000; Sampaio et al., 2002; Sandvik et al., 2003). The impact of UI can be measured in terms of 'bothersomeness' or actions taken to alleviate the incontinence, such as wearing pads, reducing activities, or seeking medical attention. Not surprisingly, women with more severe UI tend to report a greater impact (Miller et al., 2000; Burgin et al., 1991). Several scales have been developed to measure UI impact (Wyman et al., 1990; Keller et al., 1993; Wagner et al., 1996; VC, 1997) but have been used mostly in clinical trials.

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complaint' (Jolleys, 1988; Goldstein et al, 1992; Harrison & Memel, 1994), this accounts for people not seeking help.

A majority of people with UI have not sought help, (Holst and Wilson, 1988; Rekers et al 1992; Schulamn et al 1997) and this is confirmed in recent publications (Hunnskaar et al 2004; Hagglund et al 2003; Kinchen et al 2003). Reasons given by people for not seeking help include, not regarding incontinence as abnormal or serious (Holst and Wilson 1988; Reymert and Hunnskaar 1994). Considering incontinence to be a normal part of ageing (Dugan et al 2001; MacKay and Hemmett 2001), having low expectations of treatment (Holst and Wilson 1988; Reymert and Hunnskaar 1994) and thinking they should cope on their own (MacKay and Hemmett, 2001). In a Norwegian study 4.4% of all women >20 years old in a community consulted their general practitioner for UI during a 3 year period (Seim et al 1996). There are reports however of doctors not responding, either by ignoring the statement of symptoms or by providing a dismissive explanation, (Mitteness, 1987) and people interpreting a lack of response from the doctor as an indication that no treatment is available. Shaw (2001) in a study of management of incontinence in general practice, 30% of the women who had told their general practitioner about their symptoms perceived that they were offered no help.

Physical factors alone will not give a full picture of the individual and the extent to which UI is a problem. The patient's attitude to incontinence will affect the treatment options (Helman 2001). O'Donnell et al (1992) revealed in their study that most incontinent people will understandably be distressed and are motivated to try anything that might help. Others are convinced it is irreversible and have learned to accept it. Others deny the problem, even in the face of obvious evidence to the contrary. This may be because of shame, or for the simple fact of being labelled 'abnormal' (O'Donnell et al, 1992). This may reflect a psychological conflict between reality and the individual's self-image (Helman, 2001). Fillingham & Douglas (1997) state that the physical signs of incontinence are objectively demonstrable, but the effect on the quality of life, understanding of the condition and ability to cope varies subjectively.

Thomas & Morse (1991) found anxiety and depression might not only be a reaction to incontinence, but may also contribute to causing it. The affect of incontinence on sexual activity have been the focus of several studies since 1990 (Sutherst 1979; Sutherst and Brown 1980; Chaliha and Stanton 1999; Aslan et al 2005). Walters et al

complaint (Haglund, 1992). On the other hand, some research has shown that the

accounts for people not seeking help for their problem.

There are several reasons why people do not seek help for their problem.

A majority of people in the United States do not seek help for their problem.

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(1990) compared 63 incontinent women with a matched control group and found that the former reported more sexual dysfunction. Urine loss during sexual activity was reported by 34% in a questionnaire survey of 196 incontinent women (Vierhout & Gianotten, 1993) and by 56% of the 44 women in the study by Clark & Romm (1993). Chiverton et al (1996) imply the psychological effects of incontinence must never be underestimated. He claims that there is strong anecdotal evidence that suggests people whose symptoms have been present for years and have had a profound affect on their lifestyle will experience immediate relief by simply talking about their problems to someone who understands and recognises the condition (Abrams et al 1984). Macaulay et al (1991) undertook psychiatric assessments on women attending an urodynamic clinic. Their results found one-quarter of sufferers were more likely to be as depressed, anxious and phobic as psychiatric patients. Furthermore, in a study Grimby et al (1993) in comparing 120 female sufferers of incontinence with a non-suffering control group, found incontinence sufferers to be socially more isolated.

There are many people who suffer from UI, and that for many of them good treatment options are available. However, for many persons with mild or occasional UI it is probably adequate not to seek help from the health care system. Others are satisfied with just information and understanding about the causes and in many cases self-management is appropriate. Some sufferers cope reasonably well, with little apparent disruption of their lifestyle. A study carried out by Lagro-Janssen et al (1992) found that out of 123 participants only 7% said that incontinence was an extreme inconvenience. A larger proportion (23%) felt urinary incontinence had no affect on their lifestyle (Brocklehurst 1993). For those who cope less well it can become the dominant factor in their life (Grimby et al 1993).

In addition to seeking help from the formal health care system, common responses to symptoms of illness are self-management and self-treatment behaviour. The major methods actively managing UI among community residents is the use of absorbent products (Schulman et al 1997; Herzog et al 1989; Sandvik and Hunskaar, 1993). There is an association between help seeking and condition-specific factors like duration, frequency and amount, and people's perceptions of the impact of incontinence (Shaw, 1999, 2001; Roberts et al 1998; Schulman et al 1997; Hannestad et al 2002), but other more personal characteristics like individual health care behaviour and attitudes may play a role.

(1990) compared 23 incontinent women with a matched control group and found that the former reported more sexual dysfunction. Urine loss during sexual activity was reported by 34% in a questionnaire survey of 108 incontinent women (Verhoef & Glasgow, 1998) and by 56% of the 41 women in the study by Clark & Rimm (1993). Chivers et al. (1995) imply the psychological effects of incontinence must never be underestimated. He claims that there is strong anecdotal evidence that suggests people whose symptoms have been present for years and have had a profound effect on their lifestyle will experience immediate relief by simply talking about their problem to someone who understands and recognizes the condition (Adams et al. 1984). Maloney et al. (1991) undertook psychiatric assessments on women attending an urodynamic clinic. Their results found one-quarter of sufferers were more likely to be depressed, anxious and phobic as psychiatric patients. Furthermore, in a study Ghimby et al. (1993) in comparing 120 female sufferers of incontinence with a non-suffering control group, found incontinent sufferers to be socially more isolated.

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Both epidemiological and qualitative research in this field should be encouraged in order to understand cultural, religious, and personal factors for help seeking behaviour world wide (Rizk et al 1999; Dugan et al 2001; Shaw, 2001). Specifically, other than condition-specific factors should be further explored, e.g. person's health care behaviour, perceptions and attitudes. This review of urinary incontinence has shown that all these assumptions by the public are in fact false and that urinary incontinence can be treated and often cured in the majority of cases. According to Norton (1988), incontinence can be prevented at all ages, although further research is required to fully substantiate the statement.

Summary

While the literature suggests differential prevalence rates in racial groups, many have reported similar feelings of anger guilt and punishment, and the negative impact of UI on the lives of sufferers is common (Grimby et al 1993; Pinnock and Mallett 1997; Seim et al 1995, 1996; Newman, 1998; Chaliha and Stanton 1999; Fultz and Herzog 2001; Milsom et al 2001). Additionally Chaliha and Stanton (1999), Wilkinson (2001) and Doshani et al (2007) also suggest that for some women of South Asian descent additional anxieties and difficulties arise, in comparison to the indigenous population. Health information needs of people from ethnic minority groups differ due to their cultural beliefs and values (Ashing-Giwa and Ganz, 1997; Rashidi and Rajaram, 2000). Urinary incontinence remains a sensitive and to some extent a taboo subject, which needs to be brought into the open. The condition can bring stigmatisation, social embarrassment, loss of self-esteem and loss of face, and this is associated with widespread under-estimation and under-diagnosis.

With the correct diagnosis and appropriate treatment, UI can often be cured, often by simple non-invasive methods (Fillingham & Douglas, 1997). Referral can also facilitate listening to how people perceive their problems, giving a simple explanation on bladder and bowel control, and direction to appropriate resources (Hodgson (1989). The primary point of call is usually through general practitioners (Seim et al 1996). This is where the majority of health promotion and prevention should ideally take place. UI remains a highly prevalent cross-cultural and costly condition that affects women and men of all ages. Women are more likely than men to suffer from this condition. Risk factors are numerous and the impact on the quality of life is substantial. Many sufferers do not report it to health care professionals, or are reluctant to seek help. There is evidence that this may be particularly true of Asian

women, due to the low levels of services accessed generally, and the specific additional factor of religious belief. However, there is little evidence about how this community makes decisions in relation to their health needs or what prompts them to engage in a particular health activity.

The next chapter will consider some of the current decision-making and help-seeking literature. Explanatory models that have been developed over the years to predict behaviour and what instigates service utilisation will be considered in this section.

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Literature Review II

Help-seeking and decision-making behaviour

Introduction to the chapter

In the previous chapter the subject area of urinary incontinence was considered. Urinary incontinence was examined as a worldwide problem, as a problem within the UK, and from the perspective of ethnicity. The history, management and the impact of UI on the individual's life has been considered. Urinary incontinence can have a devastating affect on the life of sufferers, restricting them in many areas of life.

This chapter reviews help-seeking behaviour and outlines the main approaches in this field. Many models have been developed to understand help-seeking behaviour, which measure particular issues and a particular time. These models have been extensively used and shown their appropriateness in a given population; however they are of little use in an under-researched group, such as the Muslim communities.

I will be using MacKian's (2003) two approaches to health-seeking behaviour to provide a flow for this chapter. The two approaches MacKian discusses are '*utilisation of the formal system*' and '*illness response*'. The two approaches will be used as main headings in the text.

In the section '*utilisation of service*' I will draw upon literature around the Asian/Muslim communities to understand the process of service utilisation and folk/spiritual remedies. Further, I will discuss why there appears to be an under representation of Asian communities in research. Following on from this I will use the second approach of '*illness response*' to outline the development of some of the social cognition models.

The final section of this chapter will draw on the aim of this study: 'cultural and religious influences on help-seeking behaviour and decision making in South Asian Muslim women with urinary incontinence'.

Measuring help-seeking behaviour

Health is very important as it allows people to enjoy their life (Diener et al 1997). Illnesses or disease can have a negative impact on people enjoying their lives. How

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Measuring help-seeking behaviour

Health is very important as it allows people to enjoy their life (Dienert et al 1997). Illnesses or disease can have a negative impact on people enjoying their lives. How

an illness or disease is perceived is dependent on how a person feels at the given time. Help-seeking behaviour refers to the series of actions that an individual will carry out to rectify or resolve ill health (Ward et al, 1996). This process begins when the individual decides whether the problem is a health threat, and is defined by Gourash (1978) as '*a communication process with others focusing on a specific problem*'. It is not an isolated event and is part of a range of influences on individual, social, personal, cultural and experiential factors, which all play a role (Shaw 1999). The process of responding to 'illness' or seeking care involves many processes (Uzma et al, 1999) and cannot be translated into one simple choice or act, or be explained by a single model of help-seeking behaviour.

Utilisation of the formal system

The decision to engage in health care is influenced by many factors. According to Tipping and Segall (1995) factors that influence service utilisation are socio-economic variables, sex, age, the social status of women, the type of illness, access to services and the perceived quality of services. Service utilisation is a widely researched area with the aim of improving services for all users ⁴(Hoberman, 1992; Padgett et al 1994; Madhok 1998; Uiters et al 2006; Lyons et al 2008, to name a few).

Many studies have assessed service utilisation among many ethnic groups and in general. For example, Grilli et al (2002) reviewed the literature on the impact of the mass media on service utilisation. This review showed a positive influence upon the manner in which health services were being utilised. Similarly, Berwick (1997) stated that involving patients could also be a powerful tool in improving services. Health promotion and the subjective understanding of individuals are the two most important areas that increase service utilisation, although there is also the issue of spiritual care and folk remedies that can have a much stronger impact on the individual.

⁴ Key word search strategy:

- Service utilisation
- Ethnic minority/Minority groups
- Complementary therapies

Database search: Ovid, AMED, Medline, British Nursing Index, Google Scholar. A search was undertaken of relevant literature published between 1950 and 2008.

The search was modified to include only publications in English and those referring to humans. In addition, relevant current journals held in the University of Central Lancashire were searched. Obtained articles' references list was also examined for any articles that may be of relevance to this study.

an illness or disease is perceived as a threat to the individual's health, the individual is more likely to seek help-seeking behavior. The individual's perception of the threat is a function of the individual's knowledge of the disease, the individual's perception of the severity of the disease, and the individual's perception of the likelihood of the disease occurring. The process of recognizing the threat is a function of the individual's knowledge of the disease, the individual's perception of the severity of the disease, and the individual's perception of the likelihood of the disease occurring. (Laine et al., 1998, and references therein) The model is explained by a single model, i.e., the individual's perception of the threat is a function of the individual's knowledge of the disease, the individual's perception of the severity of the disease, and the individual's perception of the likelihood of the disease occurring.

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* Key words: diagnosis

- Disease diagnosis
- Health status
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Diagnosis is a process of identifying the disease or condition that is causing the symptoms. The diagnosis is a function of the individual's knowledge of the disease, the individual's perception of the severity of the disease, and the individual's perception of the likelihood of the disease occurring. The diagnosis is a function of the individual's knowledge of the disease, the individual's perception of the severity of the disease, and the individual's perception of the likelihood of the disease occurring. (Laine et al., 1998, and references therein) The model is explained by a single model, i.e., the individual's perception of the threat is a function of the individual's knowledge of the disease, the individual's perception of the severity of the disease, and the individual's perception of the likelihood of the disease occurring.

Within this concept of 'utilisation of the formal systems' MacKian (2003) introduces traditional healers, village homeopaths, or untrained doctors. Many individuals, groups and communities use such remedies prior to consulting with health care professionals or use them in conjunction (Ahmed et al 2001; Yamasaki-Nakagawa 2001).

The impact of spiritual or folk remedies has also been widely researched (Eisenberg et al 1993; Yeh et al 2002), however many of these studies found a much higher uptake among the ethnic groups (Bair et al 2002). The types of healers can include acupuncturists, homeopaths, herbalists, hypnotists and massage therapists. Traditional remedies have increased in their usage, as many private clinics which provide traditional treatments are now noticed in many areas in the UK. In fact, in recent research it was discovered that eight out of ten people had tried a treatment and three-quarters of them reported that it had either helped or cured them (Dein and Sembhi 2001; Schafer et al 2002).

Following a systematic review by Ernst and Cassileth (1998) in the use of complementary therapies and cancer patients, a total of 26 surveys revealed a wide range of complementary therapies used, which included, folk remedies, herbs, metabolic treatments, counselling hypnotherapy, Chinese medication and prayers. In a study by Rao et al (1999) 63% had tried some type of complementary therapies in rheumatology. Arcury et al (1996) and Astin (1998) found people who are likely to use complementary therapy are those with poor functional status, or those who are helpless about their condition (Kronenfeld and Wasner, 1982). The use of complementary therapies has therefore increased significantly in cancer patients. In a study by Swani-Sikand et al (2002) more than half of the population used some form of alternative therapies. The two main types of therapies included the use of herbs (41%) and prayers (37%). Similarly Barnes et al (2004) found the most common type of alternative or complementary therapy used among adults was prayer specifically for health reasons. This suggests that the number of people who use these therapies has increased considerably in recent years.

Service utilisation among the Asian communities

Service utilisation amongst the Asian communities is an important factor, which can help to gain prevalence rates of illnesses and diseases, success rates and satisfaction or improvement of services. As well as being important in its own right, understanding the degree of knowledge displayed by ethnic groups of the services

available to them and their attitudes to these services can help to explain patterns of their use.

Health and illness within the Muslim community is based on religion. Ahmed (1996) states that to understand the concepts of health and illness and service utilisation we must understand that British Asian communities often operate in a complex overlapping use of Islamic, medical and folk beliefs in constructing their sense of illness and disease.

Many Muslim's believe that good and bad health is from God, and therefore it is seen as a way of cleansing the soul of sin (Al-Misir and Keller, 1994). It is increasingly clear that specific attributions or causal explanations can be fully understood by taking into account the wider belief and value system of the individual. People from different cultures often make very different attributions, make attributions in different ways or approach the entire task of social explanations in different ways (Triandis, 1976; Bond and Smith, 1996; Markus et al, 1996).

Another concept, which is culturally driven and relates to the Muslim community, is of 'spirit possession' or 'evil eye'. It is common within this group to believe that 'the person's soul has been possessed, by bad spirit', which in Western medical terms can be translated into mental health disorders. These aspects are common in the Asian cultures, the idea of another person making someone ill by the use of 'witchcraft or voodoo'.

Health variations between ethnic groups are a recurrent theme in previous and recent research. Modood et al (1997) found Pakistanis and Bangladeshis report poorer health compared to Whites. Many illnesses are significantly more prevalent in certain ethnic groups for example, diabetes is more prevalent in the Asian communities, and education and non-compliance to treatment regimes have been noted as the factors related to the high prevalence (Mackeigue et al 1992, 1993, Wallace et al 1996, Rankin & Bhopal 2001). Rawaf & Bahl (1998) established that death rates from coronary heart disease among Asian people aged 65 are over 50% higher than the England and Wales average. Other factors that contribute to the high prevalence of diseases among the Asian population in the UK, according to Young (1997), could relate to a number of socio-physiological factors. However Rankin & Bhopal (2001) found the lack of knowledge about diseases was also an influential factor (Donaldson 1986, Atkins et al 1989).

These are just some of the issues that can be related to service utilisation. Many other factors have also been reported which will be discussed under the following four headings.

1. Gender of the health care professional
2. Communication
3. Knowledge, health concerns and health promotion
4. Health care systems in country of origin

Gender of the health care professional

It is widely believed that the gender of the health care professionals is related to a sense of 'modesty' especially among South Asians, particularly Muslim women. It is assumed that gender can create a barrier to consultation with a male doctor where physical or vaginal examinations are required (Wright, 1983). However, this is not entirely supported by previous research, which suggests that most South Asian women consult with male doctors and only a minority prefer female doctors (10-30%) (Jain et al, 1985; Rashid & Jagger, 1992; Pilgrim et al, 1993).

Similarly, Ahmad et al (1989) found in their Bradford study that 62% of Pakistani women said they would object to examination by a male GP, even though the majority of them did in fact consult with one. This was also identified by Day (1994) who states there is importance placed on the preservation of women's dignity in South Asian communities, resulting in hesitancy to be touched by a male doctor or to un-robe for examinations. These findings have also been reported by others (Bhakta et al 1995; Scott 1999; Matin and LeBaron, 2004). Nevertheless, it is suggested that the phenomenon may be resulting in the under-reporting of gynaecological conditions among Muslim women. However, it would appear that although problems with consultations and male professionals may sometimes be overstated, it remains a serious issue, particularly for Muslim women.

The issue of embarrassment, physical invading of privacy and lack of communication all play a major role (Elstad 1994; Kerssens et al 1997; van Elderen et al 1998; Roter et al 2001; Hilden et al 2003). Many practising Muslims have related this belief to a religious obligation, although Islamic law states otherwise (Al-Misri and Keller 1994). This paradox will be discussed further in the next chapter and in chapter 12.

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Communication

Communication is one of the major barriers among migrants (MacKinnon, 2002, pg 171), perhaps most obviously among women and elderly people from South Asian populations (MacKinnon, 2002), as is the understanding of treatment options and advice.

For this reason, many people who are unable to communicate in English tend to use their family members as a channel between themselves and the professional (Gerrish 2000). The use of family members as interpreters in medical consultations can inevitably lead to disclosure of personal information to other family members, which the patient may not be willing to share.

Previous findings raise the possibility that 'linguistic concordance' is more important than gender of the health care professional and 'it is probable that some women are tolerating unacceptable consultations because of the linguistic need to consult an Asian doctor' (Ahmad et al, 1989). This underlines the broader point that the availability of doctors from the same ethnic group does not remove all the problems that people from ethnic minority populations may experience in seeking health care (Atkin & Rollings, 1993). Many individuals from culturally diverse backgrounds seek the services of health care professionals who speak their language. When this is not possible, they are reluctant to seek care or may not understand the importance of following medical advice. Patients cannot abide by instructions if they have misunderstood what has been said by the medical professional. The problem with communication is not necessarily all down to the patient but also the professional, using medical terminology and giving patients too much to remember can result in non-compliance and a lack of understanding of the treatment.

Knowledge, health concerns and health promotion

Turning to health promotion and education, Bhopal et al (1991) argues that the health education needs of the ethnic minority groups and the majority are similar, however the techniques used to promote health in these two groups is very different. Many authors have found that ethnic minority groups have lower levels of health knowledge than the indigenous population and that this restricts many from understanding and taking up screening options (Womeodu and Bailey 1996; Goff et al 1998; Lee 2000). For example, Bhakta et al (1995) found in their studies of Asian women and breast screening that this group did not perceive themselves as being at risk. This lack of

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understanding means that members of the ethnic minority groups are less able to understand health problems than are other members of the community.

It is of interest that in the country of origin of many incoming communities the choice of the place of treatment and the gender of the practitioner is entirely the decision of the individual seeking health care, as they are paying for this care. This increases expectations of flexibility in the health care system in the UK.

Health care systems in other countries

One area that is not mentioned within the literature as a barrier is the free health care service in the UK and the private health care system in other parts of the world. This may be one of the reasons why the previous (mainly UK) literature has stated that ethnic minority groups are more likely to over utilise primary services (Johnson et al, 1983; Donovan, 1984; Watt et al, 1993). Evidence suggests that levels of GP registration are high among all ethnic groups, generally exceeding 90 per cent (Johnson et al, 1983; Donovan, 1986; Watt et al, 1993). In a West Midlands study, Johnson et al (1983) found that South Asian and Caribbean patients were less likely than the White population to refer themselves directly to hospital services, generally waiting referral from their GP.

Although this does not allow us to understand why there is such a low uptake of services within these groups, we can only assume that the factors highlighted above contribute and present as barriers. Other possible factors can include researcher bias and participation in research, which are discussed further.

Under representation of ethnic minority groups

The lack of research on service utilisation among the ethnic minority groups may be due to the unwillingness to take part in research studies (Wilkinson and Williamson 1994; Wilkinson 2001). Differences in the willingness to participate in medical research are primarily due to the lower level of trust in medical research and a lack of knowledge as to why such studies are conducted (Bhopal 1997; Marwa 2000; Stark et al 2002).

The contribution of socio-economic factors to, in particular, black-White health differentials have been investigated in many studies, however these studies have, often been limited by small sample sizes or a reliance on administrative data in which information on factors other than ethnicity and socio-economic position was not

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available (Naish et al, 1994). According to Nazroo (1997), data limitations have greatly hampered investigations of ethnic inequalities in health and how they might be structured by social and economic disadvantages.

Nazroo (2003) goes on to illustrate the impact of some of these limitations on how data are interpreted and suggests that social and economic inequalities are fundamental causes of ethnic inequalities in health. He also suggested that experiences of racial harassment and discrimination, and perceptions of living in a discriminatory society, contribute to ethnic inequalities in health (Nazroo, 2003). Bhopal (2001), found that 20-26% of the 'White' population admitted being prejudiced against Asian, Caribbean or Muslim ethnic minorities. Further Murphy & Clark (1993) recorded derogatory attitudes towards, and stereotyping of, Asian clients by health care workers and instances of insensitive treatment and poor communication with older Asian people (Rawlings-Anderson 2001). The editorial by Bhopal (2001) argues the point that racism is obvious in the medical profession, not only against the patients from ethnic minority groups, but also towards staff that are from these groups. Bhopal (2001) indicates that every member of Britain's ethnic minority population has anecdotes of racism, sometimes minor, sometimes shocking.

Marwa (2000) commented that despite notable progress in the overall health of the nation, many people who are members of racial and ethnic minority groups experience inequalities in health care and service utilisation. Nazroo (2003) agrees with Marwa and found that Bangladeshi and Pakistani people report the poorest health, followed by Caribbean people and Indian people; the Chinese and White population have reported to have the best health.

Nazroo (2003) suggests that this problem is due to poor social circumstances, although the socio-economic position of the ethnic minority remains the subject of considerable debate. Some claim that socio-economic inequalities make minimal or no contribution to ethnic inequalities in health and the use of services. Wild & McKeigue (1997) suggest that even if they do contribute, the cultural and genetic elements of ethnicity must also play a role.

This under-representation is equally due to researcher bias, inappropriate strategies for recruitment, or cost issues, translators or translations of information sheets (Stark et al, 2002; Bartlett et al 2003). Shavers et al (2000) states that excluding this group from clinical trials is unethical, introduces substantial bias, and means that findings

available (Hsieh et al. 1994). According to Nazroo (1997), data limitations have greatly hampered investigations of ethnic inequalities in health and how they might be structured by social and economic disadvantages.

Nazroo (2003) goes on to illustrate the impact of some of these limitations on how data are interpreted and suggests that social and economic inequalities are fundamental causes of ethnic inequalities in health. He also suggested that experiences of racial harassment and discrimination, and perceptions of living in a discriminatory society, contribute to ethnic inequalities in health (Nazroo, 2003). Bhopal (2001) found that 20-25% of the 'White' population admitted being prejudiced against Asian, Caribbean or Muslim ethnic minorities. Further Murphy & Clark (1993) recorded derogatory attitudes towards, and stereotyping of, Asian clients by health care workers and instances of insensitive treatment and poor communication with older Asian people (Rawlings-Anderson 2001). The editorial by Bhopal (2001) argues the point that racism is obvious in the medical profession, not only against the patients from ethnic minority groups but also towards staff that are from these groups. Bhopal (2001) indicates that every member of Britain's ethnic minority population has anecdotes of racism, sometimes minor, sometimes shocking.

Marwa (2000) commented that despite notable progress in the overall health of the nation, many people who are members of racial and ethnic minority groups experience inequalities in health care and service utilisation. Nazroo (2003) agrees with Marwa and found that Bangladeshi and Pakistani people report the poorest health, followed by Caribbean people and Indian people, the Chinese and White population have reported to have the best health.

Nazroo (2003) suggests that this problem is due to poor social circumstances, although the socio-economic position of the ethnic minority remains the subject of considerable debate. Some claim that socio-economic inequalities make minimal or no contribution to ethnic inequalities in health and the use of services. Wild & McKelvie (1997) suggest that even if they do contribute, the cultural and genetic elements of ethnicity must also play a role.

This under-representation is equally due to researcher bias, inappropriate strategies for recruitment, or cost issues, translators or translations of information sheets (Shah et al. 2002; Bhatti et al. 2003). Shavers et al. (2000) states that excluding this group from clinical trials is unethical, introduces substantial bias, and means that findings

are based on unrepresentative populations (Brawley and Freeman, 1999; Hussain-Gambles et al 2004).

To summarise:

Utilisation of formal service among the ethnic minority groups has shown that many factors will affect the individual, which is conceptualised as a 'sequence of remedial action' (Ahmed et al 2000). Although the above section has shown that due to racial discrimination people experience inequalities in health, I agree more with the issue of the gender of the health care professional, as well as problems of communication and lack of knowledge regarding health issues. There is no doubt that racism can affect many accessing services, but cultural and religious beliefs that have carried on for generations are more likely to blame than racism.

In the next section I will address 'illness response' within which I will draw upon the social cognition models that tend to predict and determine help-seeking behaviour.

are based on information available from the literature (Gambles et al 2004).

To summarise:

Utilisation of formal services is not a simple matter. It is influenced by a range of factors which affect the individual, the community and the service. A number of factors have been identified as influencing the gender of the health care provider, the gender of the patient, the gender of the knowledge agent, and lack of knowledge agent. These factors affect many aspects of the health care system, and for generations are more likely to be difficult to change.

In the next section I will summarise the main findings of the research and discuss the implications for social cognition models of health care.

Illness response

Illness response, as the term suggests, is how an individual responds to an illness by adopting health-promoting behaviours (MacKian 2003). A number of explanatory models have been developed to predict possible behaviours. According to Ogden (2000), these models are based on demographic, social, emotional, and cognitive factors, perceived symptoms, and access to care and personality, which can be used to predict behaviour.

Models developed to measure behaviour

For a number of years it has been acknowledged that health behaviour plays a role in health and illness. Theories of health behaviour and the extent to which health behaviours can be predicted by health beliefs such as the attributions about the causes of health and illness were developed. These theories of health beliefs created what we know today as social cognition models, such as 'social cognition model' (Bandura 1971) 'locus of control' (Rotter 1954), 'health belief model' (Becker 1974), 'theory of reasoned action' (Ajzen and Fishbein, 1980) 'theory of planned behaviour' (Ajzen and Madden 1986), to name a few.

Such models explain the process of help-seeking using a multi-stage process, which include acknowledging the problem, recognising the need for help, finding a balance between the problem and how to manage it, seek help or cope and control it (Keith-Lucas 1994). The following section will draw upon the most commonly used models and illustrate their use in selected studies.

All these models are theoretically linked as they all explain the subjective experience of illness, although many have been used in experimental designs. Table three identifies the main explanatory models, it should be noted that there have been many more, however for the purpose of this chapter I have only drawn on the ones that have been extensively used in research studies.

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Table 3 Explanatory models

Author	Date	Title	Focus	Concept
Rotter	1954	Locus of Control	Internal or external controls	Internal: the person believes that they control themselves and their life. External: the belief that others, including God, control their life and decisions.
Bandura	1971	Social Cognition Model	Role model	Experience: mastery Modelling: comparison between people Social persuasion: dis/encouragement Physiological factors: person's belief.
Becker	1974	Health Belief Model	Perceived threat, perceived seriousness, perceived susceptibility, perceived barriers.	Awareness: leads to a sense of susceptibility that in turn helps to motivate the development of change behaviour.
Ajzen and Fishbein	1980	Theory of Reasoned Action	Attitudes and behaviour	Attitudes: belief about a particular behaviour Subjective norm: influences of people in one's social environment Behavioural intention: function of both attitudes and subjective norm.
Ajzen and Madden	1986	Theory of Planned Behaviour	Self efficacy	Behavioural belief: about the likely consequences of the behaviour Normative beliefs: about the normative expectation of others Control beliefs: about the presence of factors that may facilitate, or impede, the performance of the behaviour.

Locus of Control

Rotter (1954) developed this concept as an important aspect of personality. According to Rotter the likelihood that a person will engage in a particular behaviour is a function of two things; the persons expectancy that the behaviour will lead to a particular outcome in that situation, and the value of the outcome to the person in that situation.

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Bandura	1977	Model Cognition Social	Role model	Physiological factors: person's belief. Social persuasion: disencouragement Modelling: comparison between people Experience: mastery
Becker	1974	Model Belief Health	perceived seriously perceived perceived perceived perceived perceived perceived	perceived perceived perceived perceived perceived perceived perceived perceived
Atten and Fishbein	1980	Theory of Reasoned Action	Attitudes and behaviour	Attitudes: belief about a particular behaviour Subjective norm: influences of people in one's social environment Behavioural intention: function of both attitudes and subjective norm.
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Locus of Control

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Locus of control refers to a person's belief about what causes the good and bad results in his or her life. Rotter stated that 'internal' and 'external' loci of control are two different ways individuals explain events in their lives. According to Ogden (2000) internal locus of control is a term that tends to explain outcomes in the control of the individual experiencing them, whereas external locus of control is a term that is used to refer to those who believe that someone or something else is in control of their life events. Rotter believed that the locus of control is learned through experiences in a variety of situations, they are thought to be stable over time, or at least in adulthood (Baum 1997).

This model has been adapted and applied to many studies in health, and developed into tools such as *Health Locus of Control Scale* and the *Multidimensional Health Locus of Control Scale* (Wallston and Wallston 1982). Applying this theory to health settings would mean that those who feel that they have control over their own health are more likely to pursue health promoting behaviours than those who feel the opposite. A study conducted by Nai-Ying and Su-Ting (2005) found health locus of control played an important role in moderating the relationship between uncertainty (of illness and disease) and informational needs. Nai-Ying and Su-Ting suggest that for people who had higher levels of uncertainty and education their belief in an external locus of control was high. This suggests that educational levels, or understanding health and illness, aid in determining whether a person has an internal or external locus of control.

This model can also be applied to the study in question. Considering the aim of the study, how do these women perceive urinary incontinence, and are they likely to seek help? As noted on page 39, many Muslim communities regard illness and wellbeing as from God, therefore indicating that they relate more to their external locus of control.

Although this theory appears interesting there are criticisms or confusions. For example Ogden (2000) states '*is it possible to be external and internal*' and '*is going to the doctor for help external* (as the doctor is seen as an 'other') *or internal* (because I am deciding my health status as poor and seeking health care?)' (pg 19).

locus of control refers to a person's belief about whether or not he or she is the master of his or her own destiny. People with an internal locus of control believe that they are responsible for what happens to them, while people with an external locus of control believe that outside forces, such as fate, fate, or other people, are responsible for what happens to them. This model has been used to explain a variety of health-related behaviors, such as smoking, drinking, and eating habits (Barn 1997).

This model has been used to explain a variety of health-related behaviors, such as smoking, drinking, and eating habits (Barn 1997). People with an internal locus of control are more likely to take control of their health, while people with an external locus of control are more likely to believe that their health is determined by outside forces. A study conducted by Barn (1997) found that people with an internal locus of control were more likely to seek help for health problems, while people with an external locus of control were less likely to do so. The study also found that people with an internal locus of control were more likely to understand health problems and seek help for them, while people with an external locus of control were less likely to do so.

This model can also be applied to the health of women. A study by Barn (1997) found that women with an internal locus of control were more likely to seek help for health problems, while women with an external locus of control were less likely to do so. The study also found that women with an internal locus of control were more likely to understand health problems and seek help for them, while women with an external locus of control were less likely to do so.

Although this theory suggests that people with an internal locus of control are more likely to seek help for health problems, it is not always true. For example, a study by Ogban (2000) found that people with an internal locus of control were less likely to seek help for health problems than people with an external locus of control. This may be because people with an internal locus of control are more likely to understand health problems and seek help for them, while people with an external locus of control are less likely to do so.

Social cognitive theory

Social cognitive theory was developed by Bandura (1971). It suggests that behaviour is socially learned, determined, or maintained. Individuals are recognised as social beings, therefore behaviour is influenced according to Bandura by the 'social' and 'cultural' environments that actively influences and mediates individual behaviour. Bandura (1977) stated that individuals change their behaviour in response to situational circumstances, and believed that individuals learn best by observation, specifically by watching others perform and modelling the behaviour. Self-efficacy⁵ is central to this theory which determines whether the action will determine the desired outcomes, and individuals' beliefs about their capacities to perform that given action (Miller and Taylor 1995, pg 7). This is the 'foundation of human agency' as Bandura (2001) states, which is the core of his work, as it determines how much effort a person will undergo to accomplish their goal.

Bandura's model has been applied to many areas of health, such as drug and alcohol use, smoking, condom use, breastfeeding, and disease management. Such studies have found strong support of the self-efficacy concept. A study by Dennis and Faux (1999) titled 'Development and Psychometric testing of the Breastfeeding Self-efficacy scale' found that those women who had experienced multiple parities were more confident in accomplishing the breastfeeding task than first time mothers, who were more likely to 'give up' the task. Bandura (1991) suggests that people who may doubt their ability in an event will consequently 'give-up'. However, those who continue will eventually master their goal. Broome (2003) applied the concept of self-efficacy to research within the continence field. Broome identified that the concept of self-efficacy was central to pelvic floor exercises, the confidence to perform, maintain and master interventions. Another area which can be explored with the social cognition model in mind is the belief about UI. For example, Bandura talks about role modelling. Taking this concept and applying it to the study can identify how people perceive this condition, how cultural and social factors that Bandura discussed influence the individual perception and behaviour related to seeking health care.

However in areas such as sport and anxiety based on self-report measures (Weinberg et al 1980; Kirsch 1990) little relationship was found between self-efficacy

⁵ Self-efficacy is defined as a person's belief that he or she is or is not capable of performing the change in behaviour required to lead to desired outcome. Self efficacy deals with people's judgements about their capabilities to perform behaviour or a set of behaviours adequately in specific situations and the influence of their perceptions on motivation and actual performance (Bandura, 1997).

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and performance. As Kirsch (1995) states, self-efficacy expectations may be more reflective of one's willingness to perform certain tasks rather than one's confidence.

The health belief model

The health belief model is probably the most widely used model in health research. As a health model, it is often related to wellness. In this model 'fear' or recognition of one's 'susceptibility' to an adverse health, outcome or illness motivates the individual to partake in health change behaviour (Becker, 1974). Rosenstock originally developed this model in 1966, to explain widespread failure of the asymptomatic US population to accept disease preventatives or to undergo screening tests for conditions such as lung cancer (Godin and Shepard, 1990). This theory was revised by Becker in 1974 (Rosenstock 1974), who remains the mostly cited author.

The health belief model is central to four constructs:

- Perceived susceptibility,
- Perceived severity,
- Perceived benefits and
- Perceived barriers (Ogden 2000).

The health belief model was developed to explain why people fail to take up disease prevention such as screening methods (Myers and Midence, 1994). It proposes that the likelihood of someone taking up screening is a function of their personal belief about the perceived threat of a disease and an assessment of the risk and benefits of the recommended action (Janz and Becker, 1984).

To summarise the health belief model, it can be stated that the perceived threat is determined from personal beliefs about the perceived seriousness of the threat and the individuals' perceived susceptibility to it. This is weighed against the perceived benefits of an action against the perceived barriers to the action (Myers and Midence 1994).

Becker and Maiman (1975) added a further component, which identifies that a cue to action or stimulus must occur to trigger the behaviour. The health belief model then predicts that the likelihood of action is increased if the perceived threat of the disease is high, if the benefits of behaviour are thought to outweigh the barriers, and if certain cues are in place (Ogden 2000, pg 24).

The use of the health belief model can be seen in many health promotion studies including those focused on breast cancer, tuberculosis, genetic disease, dental

and performance. As a result, the authors suggest that the use of
relatives or others who are not directly involved in the task may be

The health belief model

The health belief model (HBM) is a psychological model that
describes the process by which individuals decide whether to
engage in health-promoting behavior. It is based on the idea that
one's susceptibility to an illness, the severity of the illness, and
the benefits of taking action are key factors in the decision-making
process. The HBM is a useful tool for understanding why some
people take action to prevent illness while others do not. It has been
used to study a wide range of health behaviors, including smoking,
diet, exercise, and the use of health services. The HBM is a
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Becker and Marmot (1975) proposed a model of health behavior
action or inaction based on the health belief model. The model
predicts that the likelihood of action is greater if the perceived
benefits of action are high, if the perceived barriers to action are
low, and if the perceived susceptibility to illness is high. The
model also predicts that the perceived severity of the illness is
a factor in the decision-making process.

The use of the health belief model (HBM) in health promotion
programs has been found to be effective in increasing health
behaviors and reducing health risks. The HBM is a useful tool
for understanding why some people take action to prevent
illness while others do not.

disease, and influenza (Janz and Becker, 1984). Mahoney et al's (1995) study on condom use applies the health belief model. It found that students are more likely to use condoms if they perceived themselves more susceptible to HIV/AIDS.

Using the health belief model to promote continence has also been effective (Sampsel et al 2004). For example, if people believe they are at risk they then become more likely to take up services. The health belief model can allow health care professionals to assess how health promotion could be implemented within a given group and what barriers may occur.

Ogden (2000) suggests the HBM does not consider the emotional factors, such as fear and denial (pg 26). Finally, there is no account of the fact that the costs and benefits of behaviour change may vary over time (Schwarzer, 1992). This may account for varying results across studies and the fact that not all may support the health belief model (Weisenberg et al 1980). These issues gave rise to and are central to the theory of reasoned action.

Theory of Reasoned Action

The theory of reasoned action was developed Ajzen and Fishbein (1980), and was central to investigating relationships between attitudes and behaviour. The central tenets of this theory are behavioural intention, attitude and subjective norm.

Ajzen and Fishbein (1980) suggested that individuals are usually quite rational and make systematic use of information available to them. *'People consider the implications of their actions before they decide to engage or not engage in a given behaviour'* (Ajzen and Fishbein, 1980, pg 5). This theory looks at behavioural intentions rather than attitudes as the main predictors of behaviours (Conner, 1993). For example, the more an individual intends to give up smoking or carry out activities the more likely it will happen.

One of the greatest limitations was the nature of self-reporting with people who have little or feel they have little power over their behaviours and attitudes (Godin and Kok 1996). Self-reported data is very subjective and is not always accurate (Conner, and Norman, 1996). This theory assumes behaviour is a consequence of conscious decisions. Irrational decisions or habitual behaviour are not consciously considered and cannot be explained by this theory.

Following on from this Ajzen considered adding a third element to the original theory, which then became known as the theory of planned behaviour.

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Theory of Planned Behaviour

This theory is an extension of the theory of reasoned action developed by Ajzen and Madden in 1986. According to this theory, the most important determinant of a person's behaviour is behaviour intent. According to Ajzen (2005), the individual's intention to perform behaviour is a combination of attitude towards performing the behaviour and subjective norm (pg 118). The individual's attitude towards the behaviour includes behavioural belief, evaluations of behavioural outcome, subjective norm, normative belief and the motivation to comply (Ajzen 2005, pg 118-119). The added concept was perceived behavioural control, which is grounded in self-efficacy, originally proposed by Bandura.

The theory of planned behaviour and the theory of reasoned action have been applied to many health related studies including smoking cessation, exercising, healthy diet and condom use, to name a few.

Criticisms of these two theories relate to the fact that both relate to predicting behavioural intentions and behaviour but do not explain behaviour change. According to Sharma (2007) these models do not consider behaviour modification, personality-related factors, cultural factors, and demographic variables. Ogden (2003) noted that both these models are pragmatic theories, but criticised their conceptual bases and discussed several limitations, including focusing on analytic truths rather than synthetic ones.

To summarise

The above section has drawn upon some of the most widely used models within health care to predict and determine behaviour. Through the models, one assumption that can be applied is the level of knowledge an individual seeks or has, to rectify their behaviour, or show improvement in conditions. If knowledge is the key that determines behaviour change, then understanding how the study sample perceives conditions would be necessary. In chapter twelve, pg 223-228, I have drawn conclusions about how these models may or may not apply to the sample, the findings and the research question. It is worth noting that these models are extensively used and have shown positive results. However they are condition/illness specific. They emphasise stable health beliefs, are provider focused, and do not adequately acknowledge the patients' perspectives (Kleinman, 1980; Heurtin-Roberts and Reisin, 1992).

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Most of the research that has been conducted in examining the linkage between perceived control and health behaviours has been based on some form of social learning theory. Two of the major social learning theorists are Julian Rotter and Albert Bandura who have contributed key psychological constructs to the literature relevant to perceived control (Dziegielewski 2004). The health belief model is similar to the social learning model because it applies the concept of awareness, as awareness leads to a sense of susceptibility that in turn helps to motivate the development of change behaviour (Chapman 1994). Similarly, the theory of planned behaviour added the self-efficacy concept developed by Bandura.

There are clear similarities between all these models and the newer models that incorporate a concept originally developed by these models. For example, Shaw (1999) developed a model to study psychosocial variables affecting urinary incontinence. This model utilises concepts and theories from the above models discussed and explains how individuals appraise and cope with symptoms, and what effect coping strategies have on both psychological and physical outcomes.

Service utilisation and illness response are two areas that are central to help-seeking behaviour for any given condition. The next section will draw on the aim of this study and identify service utilisation for urinary incontinence.

Help-seeking behaviour and urinary incontinence

In this section, I will concentrate on help-seeking behaviour and urinary incontinence. For many people, incontinence is a source of embarrassment or shame rather than a signal to them that they should seek medical help (Norton 1982). Urinary incontinence is seen in terms of its social consequences rather than a symptom of possible underlying illness or disease process (Armstrong, 1980). Personal and social attitudes towards incontinence are not, however, the only factors that account for the under-reporting of this widespread health problem.

The fact that incontinence remains largely a hidden problem among the general population can be one of the reasons why there is a general reluctance of people to admit to their incontinence and seek treatment. The failure to report symptoms is not only limited to individuals who are incontinent. Patrick and Scambler (1986) states

Most of the research that has been done on the social control of behaviour has been done in the context of the family. Two of the most influential studies in this area are Bandura's (1969) study of the social control of children's behaviour and Bandura's (1977) study of the social control of children's behaviour. Bandura's (1969) study of the social control of children's behaviour was a longitudinal study of 111 children aged 12-17. The children were followed up over a period of 10 years. Bandura's (1977) study of the social control of children's behaviour was a cross-sectional study of 111 children aged 12-17. The children were followed up over a period of 10 years. Both studies found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura's (1969) study found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura's (1977) study found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network.

There are also a number of other studies that have looked at the social control of behaviour. For example, Bandura (1982) looked at the social control of children's behaviour in the context of the family. Bandura (1982) found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura (1982) also found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura (1982) also found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network.

Service utilisation and health status are two other areas that have been studied in the context of the social control of behaviour. For example, Bandura (1982) looked at the social control of children's behaviour in the context of the family. Bandura (1982) found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura (1982) also found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura (1982) also found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network.

Help-seeking behaviour and health inequalities

In this section, I will consider the social control of help-seeking behaviour. For many people, help-seeking behaviour is a complex process involving a number of factors, including the individual's personality, the individual's environment, and the individual's social network. Bandura (1982) found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura (1982) also found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network. Bandura (1982) also found that the social control of children's behaviour is a complex process involving a number of factors, including the child's personality, the child's environment, and the child's social network.

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that it has been estimated that only 20% of people needing treatment for illness of any kind attend for medical advice.

As previously noted symptoms of urinary incontinence can be stigmatising and embarrassing and are often neglected, resulting in low uptake of services (Shaw, 2001). Despite the impact of incontinence, a large proportion of incontinent women do not discuss symptoms with a doctor. One study of middle-aged women found that even among those with daily incontinence, only 54% reported seeing a doctor about their symptoms (Brocklehurst, 1993). Reports range from 19-50% of people with incontinence consulting their doctor (O'Brien et al 1991, Dolan et al 1999, Stoddart et al 2001). One study estimated that in the UK, only 15% of those with stress urinary incontinence symptoms had consulted a doctor (Hunskaar et al, 2003). A number of factors have been cited to explain the help-seeking behaviour of women with incontinence, including patients' perceptions of the severity of the condition, the embarrassment of talking about incontinence (Simons, 1985) and the belief that incontinence is a normal part of ageing (Mitteness and Barker 1995).

Studies exploring the reasons for low levels of help-seeking find that embarrassment, lack of knowledge of treatment and misinterpretation of cause are some of the reasons for non-consultation (Shaw et al 2001), but it is possible that symptoms are simply not bothersome enough and do not impact on the quality of life of those who do not seek help. As Perry et al (2000) found although around one-third of people over the age of 40 years reported clinically significant urinary symptoms, only about 3% found symptoms to be socially disabling.

The severity of the condition also has a relationship with outcomes of psychological distress and impact on activities. The more severe the leakage, the greater the distress and the more restricted activities become (Yarnell et al 1981; Herzog et al 1988; Lagro-Janssen et al 1990; Samuelsson et al 1997; Heit et al 2006). Severity of the condition is an important variable to consider in relation to help-seeking behaviour. When assessed in terms of frequency of leakage, amount of leakage and use of aids to contain the leakage, the more severe the problem, the more likely a person is to seek help (Burgio et al 1991, 1994, Samuelson et al 1997).

Measures of severity often depend on self-report by the individual but are generally based on quantifiable assessments of volume and frequency and are therefore considered 'objective' measures. Before a person decides whether to seek medical help, they must make a decision as to whether the symptoms represent a health

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threat, the severity of the threat, and the resources available to cope, which are key areas of the HBM. Many sufferers will initially take up self-management strategies to rectify their symptoms, such as increasing fluids to clear the system of infections, urinary tract infections, cystitis etc (Kart et al 1992, pg 227).

Self-management

It is fairly self-evident to state that how well an individual is coping should be assessed by the individual themselves. Lazarus and Folkman (1984) defined coping as '*ongoing cognitive and behavioural efforts to manage specific external or internal demands*'. Urinary incontinence is not perceived as an illness or disease, and many individuals learn to either live with or self-manage their symptoms. The majority use coping strategies aimed at concealing leakage and maintaining self-esteem (Mitteness, 1987; Pinnock and Marshall, 1997). There is a danger, however, that those who do not seek help rely on practices that may exacerbate the problem or produce psychosocial difficulties, for example fluid restriction, frequent bladder emptying, or avoidance of social situations (Shaw 2001; Horrocks et al 2004).

Help-seeking behaviour, Urinary Incontinence and the Muslim woman

While the literature suggests that feelings, beliefs and practices related to UI are generally similar between the Muslim population and White population (Newman 1998; Cooper et al 2003; Gray et al 2003; Mason et al 2003; Hunskaar 2004), there are also additional anxieties and difficulties that Muslim women may encounter. In comparison to the indigenous population, the health information needs of people from ethnic minority groups differ in relation to cultural beliefs and values and their affect on health care practices (Ashing-Giwa and Ganz, 1997; Rashidi and Rajaram, 2000).

Chaliha & Stanton (1999) illustrate the potential differences in lifestyle that may be affected, and the difficulty in the recruitment of patients with symptoms such as incontinence. Similarly, Wilkinson (2001) reported Pakistani Muslim women had low self-esteem due to leaking urine as it prevented them from praying. Doshani et al (2007) also found many of the women in their study suffered in silence, as they were too embarrassed to seek help. Not only is there a need to increase knowledge about UI in the community, there is also a need to increase and take up a proactive approach when dealing with urinary incontinence (Doshani et al 2007).

If leaking urine restricts Muslim women in carrying out their religious obligations, they may be more than likely to seek health care. However, this is not necessarily the case as common barriers of language and family pressures all contribute to preventing people seeking health care. Wilkinson (2001) found Pakistani women felt that health care professionals were not interested in their problems and did not provide adequate support, thereby restricting their ability to seek further services. Many studies have indicated that although direct racism is certainly present in the delivery of health care to ethnic minority populations, (Wright, 1983; Larbie, 1985; Kushnick, 1988; Fenton, 1989; Ahmed et al, 1991; Atkin & Rollings, 1993; Bowler, 1993), more complex problems also arise through difficulties of communication and ethnocentrism⁶, which may also result in less satisfactory service provision.

Summary

This chapter has provided relevant literature regarding urinary incontinence and health-seeking behaviour. I have drawn upon the factors that influence people seeking help and those that discourage this. Urinary incontinence is an embarrassing subject especially for those who suffer from the problem. For an individual to respond to a illness they must first of all decide for themselves whether the problem is creating a barrier to continuing with their daily activities.

Individuals usually discuss problems with those that are close to them, for example family members and friends, which enable them to make a decision to seek help from a professional or to self-manage. This may not be the case with symptoms of urinary incontinence. Many people prefer not to mention their incontinence to others, and so the opportunity for friends to encourage them to seek advice does not arise.

⁶ Ethnocentrism is unconscious - it is predominantly a product of enculturation. Five aspects of this unconscious belief system can be particularly damaging to ethnic minorities (Patterson, 2005).

1) A strong belief in the superiority of all other group's cultural. 2) A belief in the inferiority of all other groups' cultural heritage that extends to their customs, values, traditions and language. 3) Power to impose standards. 4) Manifestation in Institutions. For example, education systems, management systems. 5) The Invisible Veil. "Since people are all products of cultural conditioning, their values and beliefs (world view) representing an invisible veil that operates outside the level of conscious awareness. As a result people assume universality: that the nature of reality and truth are shared by everyone regardless of race, culture, ethnicity or gender."

Racism on the other hand is conscious - the need to boost one's own self-worth by denigrating a person of differing skin colour or different cultural practices (Patterson, 2005).

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Knowledge of how UI is viewed within any given society is necessary for health promotion activities to be effective. Most of the models discussed are central to the individual characteristics and tend to 'blame the victim' for inadequate behaviour, taking on a Western medical perspective, in which the context in which health-seeking behaviour operates is not appropriately addressed. MacKian et al (2004) stated that there is a need for developing a tool for understanding how populations engage with health systems, rather than using help-seeking behaviour as a tool for describing how individuals engage with services.

Wallman and Baker's quote allows an understanding of this process:

"To understand the way people make decision is to understand ... the way an actor experiences them, therefore, taking a crucial step towards understanding why and how people do what they do" (Wallman and Baker, 1996).

Previous research has identified that many Muslim patients use the terms religion and culture in relation to health care (Day 1994; Wild and MaKeigue 1997; Ahmed et al 2000). In order to frame this specific study the following chapter will explore Islam as a religion and as a culture.

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Literature Review III

The Muslim culture and the Islamic faith

In the previous chapter, help-seeking behaviour amongst the Asian communities has been identified. The importance of this for health care and service utilisation has also been noted. Factors have been considered that impact on people seeking health care, including culture and religion. In this chapter, I intend to explore the Muslim culture and the Islamic faith and how these two fundamental aspects affect help-seeking behaviour.

I will begin with definitions of religion and culture, and describe the emergence of such terms of ethnicity, race and 'Asianness'.

A personal perspective:

Whilst writing this chapter I have found it extremely difficult to separate myself from the literature about the beliefs, values and practices of the Muslim communities and their religion and the media. I have come to this from a similar cultural and religious background, which is fundamental to who I am. Therefore, in this chapter when I discuss culture and religion my prior position needs to be taken into account. I will provide footnotes throughout the chapter in areas where I found it difficult to separate my own views and pursue an objective stance.

Defining Culture and Religion: is there a difference?

Many authors have defined culture in different ways. Culture generally refers to patterns of human activities. Definitions of culture reflect different basics of understanding behaviour (Levi-Strauss 1966, Barthes 1973, Geertz 1973, Burke 1978, Douglas 1988, Turner 1995, 1997). A broad definition of culture covers the whole product of an individual, group or society of intelligent beings (Helman, 2001).

Table four below identifies some definitions of culture.

Table 4 Definitions of culture

Author (s)	Definition of culture
Tylor (1871)	'Culture or civilisation, taken in its wide ethnographic sense, is that complex whole which includes knowledge, belief, morals, law, customs and any other capabilities and habits acquired by man as a member of society'.
Wundt (1897)	'A collective phenomenon'.
Boas (1930)	'The social habits of a community'
Fejos (1959)	'The sum total of socially inherited characteristics of human group that comprises everything which one generation can tell, convey, or hand down to the next'.
Smith and Bond (1998)	'A system of shared meaning'
Helman (2001)	'The way of life for an entire society'.
Mohammadi et al (2007)	'As a learned human behaviour, social organisation, structures and ideology that belong to a particular social group'.

As difficult as it is to place a definition on the term culture, it is part of the existence of all humans and animal species. Cultural traits are so deeply ingrained that they seem to be more unconscious existence than a conscious thought. Most of the things we do or consider right or wrong, the very way we behave is greatly influenced by our cultural background. Fejos (1959) described the concept of culture simply by picturing it as the language that each individual carries around for their lifetime (pg 11-35). This 'language' includes the beliefs, practices, habits, likes, dislikes, norms, customs, rituals that are learned from families, through childhood development, and socialisation. This process continues through generations, and can be described as 'cultural luggage' or 'cultural baggage' (Hart, 1998, pg 4).

In essence, 'culture' is the expression of group norms at the national, social and ethnic levels (Kelman, 1997). It also includes religion.

Religion is a concept which is difficult to define, although all existing definitions are similar. Wullf (1985) suggests when placing a definition on religion the person doing the defining must take into consideration their own methodological assumptions:

'How one defines religion, it is apparent, determines in large measures where one will look for its representations' (pg 40).

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'How one defines religion is as important, sometimes in large measures where one will look for its representatives' (pg 40).

For example, Durkheim and Weber insist that religion should be defined sociologically, Feuerbach, Freud and Jung define it psychologically, Levi-Strauss and Firth define religion anthropologically, and Rahner, Tillich define it theologically (Jones 2006). Each of these scholars emphasise what they feel to be the most important aspect of religion, which is based on their methodological assumptions. All definitions hold that religion is an inner belief and something very personal. Table four draws attention towards some of the definitions of religion. Spirituality is often used in conjunction with religion, and implies a broad grasp of the search for meaning that goes on within every human life (Wallace, 1979). In contrast, religion can be seen as a belief in a specific supernatural force.

Alston (1967) suggested eight characteristics that set out practices of a religion. These are a) belief in supernatural, b) distinction between sacred and profane, c) ritual acts, d) moral code(s), e) religious feelings, f) prayers, g) a world view and the place of the individual therein, h) one's life based on worldview, i) a social group, grouped together. Religion gives the person a frame of reference and a perspective with which to organise information, it is a complex and multi-dimensional domain of human life consisting of behaviours, attitudes, beliefs, experiences, and values.

In the broadest terms, three approaches are generally taken to the study of religion: a) the historical (the sacred texts) in this case the Holy Quran, and the Hadith. b) The phenomenological (directed towards discovering the nature of religion), and c) the behavioural or social – scientific (the psychology, sociology and anthropology). Levin and Vanderpool (1992) describe religion as 'multifaceted health-related phenomenon', considering public and private behaviours, experiences, values and norms. This definition was built upon by Schleiermacher (1988) who defined religion as a non-rational feeling or experience of the whole or the Holy.

It is apparent that religion can be seen as a theological, philosophical, anthropological, sociological and psychological phenomenon of human kind. To limit religion to only one of these categories is to ignore its multifaceted nature and not gain complete definition. However in this study, I will consider religion as: '*an inner belief and something very personal*' (Carroll 2001; Miles 2001), described by the participants themselves therefore taking the Levin and Vanderpool (1992) approach, which is also in line with the theoretical approach taken in this study. This is one interpretation of religion taking an individualistic view that there is some meaning and purpose for their lives, by ways of gathering and interpreting phenomena, making

judgements and living ethically, rather than a collective or institutional aspect of religion. The concept of religion and culture are referred to throughout this study as participants stated these two areas influenced their whole life, including experiences, coping, relationships, their roles, family, social life and language. It is a behavioural definition where actions, patterns and practices are done because of individuals beliefs about what is important in their life. Separating the two concepts for the participants in this study was impossible, as religious beliefs, practices and values were so interlinked that changing cultural views meant changing aspects of their religion.

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Table 5 definitions of religion

Author(s)	Definition
Otto (1958)	'The awareness of 'the idea of the holy'.
Wallace (1979)	'Spiritual is a term which is often used to replace religion'...'Whereas religion is the belief in the supernatural'.
Reese (1980)	'An institution with a recognised body of communicants who gather together regularly for worship, and accept a set of doctrines offering some means of relating the individual to what is taken to be the ultimate nature of reality'.
Reed (1987)	'A set of personal views and behaviours that express a sense of relatedness to the transcendental dimensions or to something greater than the one'.
Schleiermacher (1988)	'A non-rational feeling or experience of the whole or the Holy'.
Wiebe (1991)	'A kind of pre-rational belief in worship of supernatural or superhuman beings such as Gods or God'.
Barnes (1997)	'Any perspective by which people relate positively to the ultimate context of their being'.

The difference in definitions

Referring to the above two tables (tables four and five) there is not a clear difference between the definitions of culture and religion. Indeed, 'culture' seems to have the concept of religion embedded in it. Religion gives a person a frame of reference and a perspective with which to organise information and their life. Religion is a complex and multi-dimensional domain of human life comprising behaviours, attitudes, beliefs, experiences, values and so on, which are all facets of culture (Levin and Vanderpool 1992). Religion shapes a way of life, which is then reinforced through cultural practices.

In this section, I will use Islam as a religion and the Muslim culture to try to distinguish between the two, where this is possible. Prior to this I believe it is useful to explore how Britain became a multicultural society.

Table 5 Definitions of religion

Author(s)	Definition
Otto (1958)	'The awareness of the idea of the Holy.'
Wallace (1987)	'Spiritual is a term which is often used to replace religion. Whence religion is the belief in the supernatural.'
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Reed (1987)	'A set of personal views and behaviours that express a sense of relatedness to the transcendental dimension or to something greater than the one.'
Schleiermacher (1885)	'A non-rational feeling or experience of the whole or the Holy.'
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Britain as a multicultural society

Table 6 Ethnic movements into the UK

Time-line	Ethnic groups
250-1066	Arrival of the Romans. Followed by Jutes, Angles Saxons and the Vikings.
1500-1772	1505: African slaves arrived.
The 1800s	Arrival of Indian servants.
1830-1850	Irish arrived in Britain, fleeing poverty. Black and Chinese seamen arrived.
1914-1945	Bengali seamen arrived.
1946-1971	Rebuild post-war Britain: arrival of Poles, Italians, and West Indians. <i>22nd June 1948: the day became a massive change to British society, the start of mass immigration to the UK.</i> (www.news.bbc.co.uk/hi/english/static/in_depth/uk/2002/race/short_history_of_immigration.stm).
1972-1979	African Asians arrived from Uganda.
1980s	Largest groups of immigrants were Americans, Australians, New Zealanders and South Africans, South Asian men.
1987-2002	Growth of asylum seekers from Africa, Indian subcontinent, Asia, America.

Cultural shifts have had a long-standing place in the history of immigration to and from the UK (see table six above). Migration to and from a wide range of countries has allowed many different cultural groups to settle in Britain. Early population movements began in pre-historic times (Johnson 1992). Arrivals into the UK brought along with it different religions. The arrival of Jews was between the years 1066-1290 and particularly 1881-1914 (Baron 1990). Muslim arrivals in the UK took place approximately in the 1500s (bbc.co.uk) which increased dramatically in 1869 following the opening of the Suez Canal (located between the Mediterranean and the Red Sea) as most of these Muslims were seamen (bbc.co.uk).

In today's multicultural society, people are in contact with others who are from different cultural, religious and ethnic backgrounds, through employment or socialisation. It is therefore important to understand that individuals have different ways of viewing things in terms of, for example, dressing, eating habits, and gender differences. A lack of understanding of other cultures or religion can lead to the stereotyping of minority ethnic groups, which results in differential service delivery (Murray and Brown 1998, Davies and Bath 2001, Burr 2002). However, generalisations are often dangerous, as one should not assume that just because

people appear to be from similar backgrounds they will all act and react in the same way (Beckett and Maynard, 2005, pg 179-180).

Defining ethnicity, race and 'Asianness'

Through this movement, terms emerged that identified those that had migrated. Pilkington (2003) identifies three terms: 'non-White people', 'people of colour', and 'minority ethnic groups', to describe individuals that have migrated to the UK. These terms have also been used in previous research studies to identify 'race' as a risk factor for illness or certain diseases. Bhopal (2001) simply defined race as the group people belong to as a result of a mix of physical features, ancestry, and geographical origins, as identified by others or, increasingly, by self. Madhok et al's (1998) definition was much broader and included social and political heritage, making its usage similar to ethnicity. Race is used to identify groups of people, however many debates have shown this term does cause confusion (Adams 1996, Appiah and Gutmann 1996, Casey 1996, Shields et al 2005, Tillman 2000).

The term that has replaced race in research is 'ethnic group'. 'Ethnic' refers to shared cultural characteristics and national identity (Oxford dictionary pg 257). Within each ethnic group there are sub-groups, for example Muslim Asian can refer to Indian, Pakistani and Bangladeshi, or British communities. They may all share the same umbrella term but have different cultural beliefs and values. Ethnicity is therefore defined as a group of people that belong together as a result of a mixture of cultural factors that include language, diet, religion, ancestry, and race (Bhopal, 2000). Religion is an element of culture and identity, which also serves an important function, including the development of identity, belonging, and social relations. Culture was not the only component that migrants brought into the UK; different religions also form part of this multicultural society. Christianity is the majority religion reported at 71.6% of the population, followed by Islam at 2.7%, Buddhism 0.3%, Sikhism 0.6%, Hinduism 1%, Jewish 0.5%, other religions 0.3%, no religion 21.7% (www.nationalstatistics.org).

Islam in Britain

There are two million Muslims living in the UK today, which implies that the Islamic population has increased by 400,000 since the last census in 2001, making this the most common religion after Christianity (www.nationalstatistic.org). In 2003 Islam

people appear to be from similar backgrounds they will all act and react in the same way (Baker and Maynard, 2002, pg 178-180).

Creating ethnicity, race and Asianness

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was practised by over 17 percent of the world's population (Bolaffi, 2003, pg 286), with an increase to 19.2% in 2008 (Kington, 2008). Sixty-nine per cent of UK Muslims are from the Indian sub-continent (www.salaam.co.uk).

In April 2001, the decennial census divided South Asians into three ethno-national categories, Indian, Pakistani and Bangladeshi. It allowed further analysis of the social-demographic characteristic of the Britannic South Asian populations. The variations have also allowed researchers to observe patterns of language use, religion, knowledge, education, disease prevalence and management.

For people to understand Islam and the way Muslims behave and react, they must first understand the fundamental beliefs that underline such practices. The best place to begin would be the background to Islam. Any attempts to understand a society cannot fail to take into account its religious views. Eliade (1982) is one of the most influential scholars in the field of religion who states *'to understand religion one must understand the influences of culture, living as a human being is per se a religious act, to be or to become, human means to be religious'* (pg 113-127). Religion is part of ideas and experiences developed through part of a culture. For example within the Muslim communities, 'Ramadan' and 'Eid' are both religious and cultural, and which all celebrate together. There is also the need to consider the interpretations of the scholars of each sub-group of Islam. An example of this is the Shi'a community, who inflict pain to themselves on the first Islamic month. This is due to the belief that they must feel the pain of what happened in history. This is where conflicts take place between Sunni and Shi'a communities. Islam does not allow Muslims to hurt themselves or others in anyway.

Short background to Islam: as a religion

Islam is the world's second biggest and fastest growing religion, with followers mounting up to approximately 19.2% of the world's population (Kington, 2008). With a religion so huge, it is not possible to give a full history of the religion, therefore a brief introduction to Islam is provided⁷.

To understand religion it is wise to enter into the lives of those, for whom such ideas, beliefs, values and practices are important. Islamic practices and behaviour are not only related to divine revelations but as a theology, generate particular social practices in culture, manners, food and language. According to Ahmed (1999), Islam

⁷ My teachings are based on the Sunni Muslim, and this is the view I am referring to throughout. This literature is supported by the two original sources of Islam, the Holy Quran and the Hadith.

is both sociology and a philosophy for life. Islam means '*submission*' and has a moral code as well as a civil law with a unifying ethical framework. It creates a monotheistic culture, the aim of which is to create peace in one's self, family, and society by actively submitting to and implementing the will of God (Gordon, 2002).

The fundamentals of Islam as a religion are as follows:

The oneness of God

Muslims follow a strict monotheism with one creator who is the just, omnipotent and merciful 'Allah'. The term 'Allah' shows no plural or gender, unlike the term 'God' that may take a plural sense 'Gods' and a feminine form 'Goddesses'. The belief is one God or creator, which is also shared by followers of Judaism and Christianity (Burke, 2004). This is the most important fundamental teaching of Islam, the oneness of God, which is termed 'tawheed'. This is explained in the Shahdah (witness), the first article of faith, which is referred to as the first pillar of Islam: the believing of (bringing belief):

'I testify that there is no God but God Almighty, who is one (and the only one) and there is no associate with Him; and I testify that Muhammad (peace and blessings of God be upon him), is His messenger'.

Every Muslim will recite this taweed, which is a statement that makes a person a Muslim. It implies that everything in existence originates from the one and only creator. Muslims believe all good and bad are from God himself. The belief that God has given humanity the knowledge to help himself is another miracle Muslims truly believe in. However, whatever happens in a lifetime, was always planned by God, and therefore should not be challenged in any way. For example, if ill-health comes your way, you should seek help, but if it is not resolved or made better in anyway, then it should be accepted. Muslims believe that the present life is a trial for the preparation of the new and peaceful life after death. For Muslims the soul carries on to heaven or hell, and as a believer, you will be punished or rewarded for your acts on earth.

The Prophet Muhammed (SAW)

Islam was founded in 622 AD by Mohammad (saw)⁸ the Prophet, in Makkah. Technically, it is the youngest of the world's major religions, but Muslims do not view

⁸ SAW (Sal Allah o alaihe Wasalam): Arabic term used towards the end of the prophet Muhammed name, to show respect. The direct translation 'may blessing of Allah and peace be upon him'.

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I testify that there is no God but God (Allah), who is one (and the only one) and there is no associate with Him; and I testify that Muhammad (peace and blessings of God be upon him), is His messenger.

Every Muslim will recite this tawheed, which is a statement that makes a person a Muslim. It implies that everything in existence originates from the one and only creator. Muslims believe all good and bad are from God himself. The belief that God has given humanity the knowledge to help himself is another miracle Muslims truly believe in. However, whatever happens in a lifetime, was always planned by God, and therefore should not be challenged in any way. For example, if ill-health comes your way, you should seek help, but it is not resolved or made better in anyway, then it should be accepted. Muslims believe that the present life is a trial for the preparation of the new and peaceful life after death. For Muslims the soul carries on to heaven or hell, and as a believer, you will be punished or rewarded for your acts on earth.

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it as a new religion. They believe that it is the same faith taught by the prophets, Abraham, David, Moses, and Jesus. The role of Mohammad (saw) as the last prophet was to formalise, clarify the faith, and purify it by removing ideas which were added in error.

The Holy Books

The two sacred texts of Islam are the holy Quran (Koran) which are the words of Allah, as given to Mohammad, and the Hadith, which is a collection of the Prophet Mohammad's teachings and the way he lived his life. The Quran is seen as an eternal and immutable truth, the framework and principles of the law. According to Paladin (1998) the application and interpretation of the law changes with each age. Islamic law, then is in spirit dynamic and flexible, exemplified by the idea that 'necessity renders the prohibited permissible'. The four main concerns of Islamic ethics are similar to that of other ethical systems, autonomy, beneficence, non-maleficence, and justice (Van Bommel, 1999; Burke, 2004).

The Quran contains 30 distinctive chapters, which are known as *suraths*, and 6226 verses. The Quran verses are taken to mean the literal words of Allah, and should not be tampered with in any sense. The main theme of the Quran is again the oneness of God, and the belief in the Muhammad (saw) as the last messenger. The original version of the Quran was in Arabic although now it has been translated into many languages for an easy read, English is one such language⁹.

The Hadith, sometimes referred to as the *Sunnah*, is inspired by Allah, and contains words of the prophet Muhammad (saw). The Hadith is the narration of the life of the prophet Muhammad (saw). Within the Hadith the Muslim would search for answers on how to live a true Muslim life, following the prophet's footsteps, answers are within it when Muslims are faced with problems, including ill health. The Hadith is regarded as the second book of Islam but not as highly important as the Quran¹⁰.

⁹ There are no authors for the Quran itself as Muslims believe these are the words of Allah. The separate chapters and verses were brought together by Hazrat Zaid Bin Thabit. The words of the Quran have not been changed in any form, and remain original from the time of the prophet Muhammed (saw).

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The Five Pillars

The duties of Muslims are known as the five pillars of Islam, and are the model framework that all Muslims around the world will follow in relation to their daily activities, lifestyle and practices.

1. Faith: 'the oneness of God' as described above.
2. Prayers: performance of *Namaz* prayers five times a day. This is a very important tenet of Islam and has been enjoined with great emphasis in the Quran and the Hadith.
3. Fasting: during the holy month of Ramadan, *Roza*. This particular month is of special significance because this is when the holy Quran was revealed to the prophet (saw), therefore Ramadan is believed to be a celebration of the Quran itself.
4. Donation: donate regularly to charity; *Zakat* is the donation of 2% of your savings to the poor and needy. Zakat is an act of worship that purifies one's wealth.
5. Pilgrimage: make pilgrimage to Makkah; *Hajj* is the largest annual gathering of Muslims. The Ka'bah is the place of worship, which was built over four thousand years ago, in the city of Mecca.

These are the fundamentals of Islam. However, following the death of the prophet Muhammad (saw) sub sects of Islam appeared, which are described below.

Divisions in Islam Interpretation by scholars

Although Islam is regarded as one religion, there are obvious different interpretation of the Quran and the Hadith. Islam is divided into two main groups, Sunni Muslims and Shia Muslims. Both groups share the most fundamental Islamic beliefs. The difference between the two initially stemmed from political differences, which naturally gave rise to differences in religious and cultural practices.

Following the death of the prophet Muhammed (saw), Sunni Muslims felt the leadership should be taken by one of the companions of the prophet, Abu Bakr who was the dearest friend of the prophet and his companion. On the other hand, the Shia Muslims felt that the leadership should remain in the family of the prophet himself, which directly passed on to Ali, the son-in-law of the prophet. The division has in turn affected aspects of spiritual life, which are visible between the two groups.

It is important to note that, despite the differences in these groups, they share the main fundamental belief in 'oneness of God' and the belief in the saying of the holy book the 'Quran'. Shia Muslims, however, reject the teachings of the prophet Muhammad (saw) through the Hadith, and do not base any of their religious practices on this testimony. Sunni Muslims is an umbrella term used for other sub-groups within this community, as in the example below:

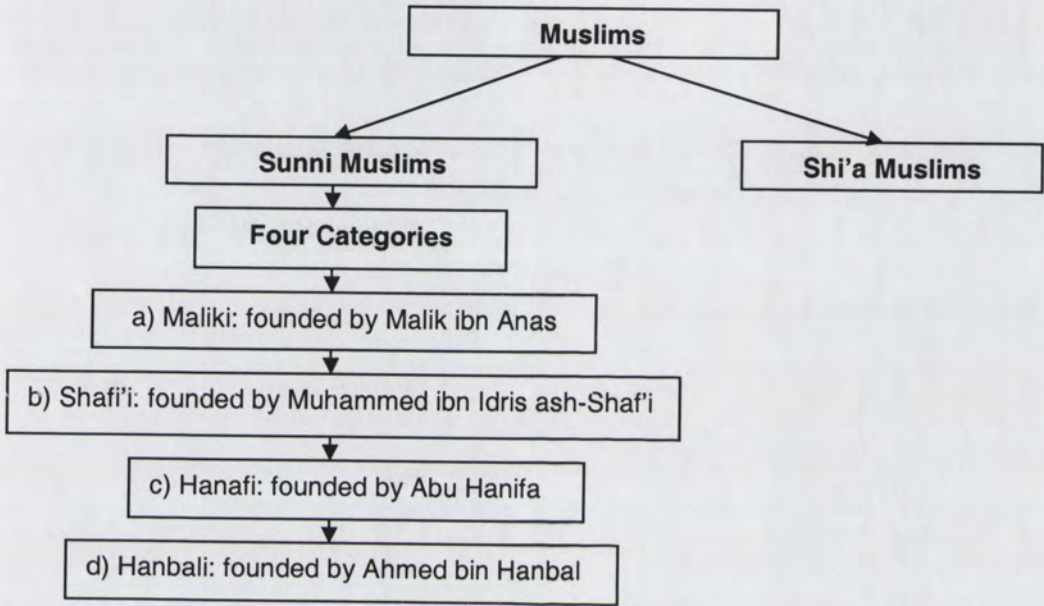


Figure 1 The division in Islam

The above sub-sects of Islam developed through the interpretations of the different scholars of Islam. For example scholars who interpreted the Hadith in different ways, as identified above, founded all the four major Sunni schools. Fatwa (Islamic ruling), have been declared by many of the scholars in Islam. Those who are knowledgeable and have wisdom in the teachings of the Quran and Hadith undertake the pronouncing of such fatwas.

It is not uncommon for different scholars to draw different conclusions regarding the same issues, for example, some scholars say that it is wrong to even talk to non-Muslims. Other scholars have stated women and men should not mix in the same environment for employment or schooling purposes. It is however not my intention to draw on such rulings, but to introduce this faith.

Now that we have determined the religious ethics, we must turn to the Muslim culture. Here I shall provide some of the aspects of this culture, so an understanding of the difference between culture and religion can be seen.

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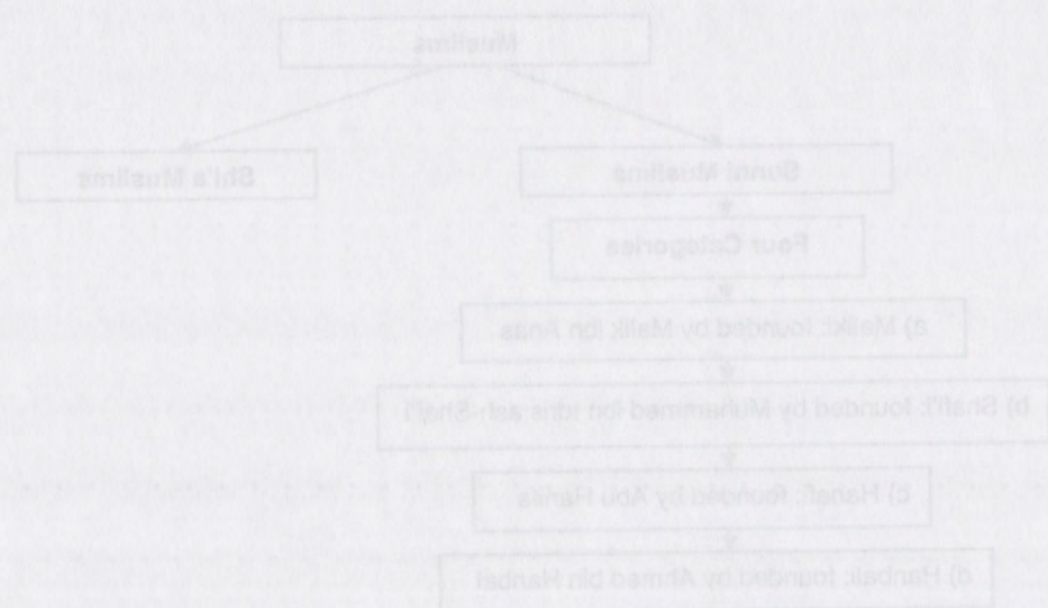


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Background to Islam: as a culture

All cultures have a range of norms, values and assumptions, which can create sub-groups within the larger cultural groups or societies (Mohammadi et al 2007). This is particularly true for the Muslim culture, due to the divisions made by many scholars.

The *Shariah* is the term that is used to mean Islamic law, which translated means 'the path' (Burke, 2004). The shariah includes laws concerning religious matters, lawful and unlawful acts, as well as daily life matters, including marriage, divorce, inheritance and the role of women to name a few. All aspects of a Muslim's life are therefore governed by the shariah, with a combination of the Quran, the Hadith and the Islamic scholars¹¹.

The Muslim culture is a term used to describe all cultural practices common to many Muslims around the world. For example, Muslims are known to have larger families than the White majority, and to have a tendency to live in towns close to each other (www.nationalstatistics.org). For a Muslim, this increases a sense of security and provides support. Muslim communities tend to live in close proximity to each other, and are based on shared and common thoughts, beliefs and practices. As seen from the above definitions, culture constitutes a wide range of factors, including how people view their life and their roles within the wider society. These factors cannot be listed as they will vary from group to group. However, the foundation of the Muslim culture is the family (IPCI 1989, pg 23).

Family

In any Muslim person's life there are two influential factors. The first and most important is that of the fundamental beliefs of Islam and secondly the family dynamics, the foundation of the Islamic society. The family is the fundamental component within the Muslim culture that determines acts and behaviours (IPIC 1989, pg 25).

Family life to the Muslim community is of great importance and is considered the foundation of Islamic society (Doi 1984). Another feature of Asian family life is the

¹¹ It should be noted that these texts would be different for the sub-groups of the Sunni sect and for the shi'a sect. These following factors have been devised by my own beliefs and do not recommend any particular position.

prevalence of three-generation households, where couples continue to live with their parents after they have started a family of their own (Anwar 1994).

Elders of the family are looked upon as having hierarchical positions, and are respected for their accounts of their life experiences. The strain of caring for one's parents in this most difficult time of their lives is considered an honour and a blessing, and an opportunity for great spiritual growth. In Islam, serving one's parents is a duty second only to prayer, and it is their right to expect it. This belief is also emphasised in the Quran:

'Your Lord has commanded that you worship none but Him, and be kind to parents. If either or both of them reach old age with you, do not say 'uff'¹² to them or chide them, but speak to them in terms of honour and kindness. Treat them with humility, and say, 'My Lord! Have mercy on them, for they did care for me when I was little.'

(Al-Isra, 17: 23-24, Quran).

There are many aspects of a Muslim way of life that can be considered and elaborated on, however due to the word limit and the study not all areas that affect the Muslim way of life can be included. The following passage presents one of the aspects that have caused controversy in the Muslim world, and which have received intense media coverage. This is also an aspect of particular relevance to this study.

Islam and women

The role of women in any society or community is mediated by multiple factors, i.e. political and economical factors, religious and cultural controls and social discourse that articulates the norms of their community (McNeal 2008). The following passage identifies literature from the Quran, Hadith and the Shariah, which may help to distinguish the essential role of Muslim women in Islam¹³. The wider text will also be considered, to identify the way in which the Western society views Muslim women.

¹² Uff: is a dismissive term, to mourn.

¹³ The status of women in Islam has recently been subject of much controversy. In the Western world, opinions about Muslim women's lives are often based on prejudice and ignorance from the point of view of outsiders, and from Muslim men, neither of which are helpful or accurate. In Asian cultures, men have the right to control their wife's behaviour and women do not challenge this right. Women are expected to look after the house and the children and to show obedience and respect to the man who is expected to provide financial support to the family.

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The view of Muslim women in the Western world, and sadly in the Muslim world, is that of *second-class citizens who have been under control of their male counterparts whether father, husband, brother, parents or the extended family* (Helie-Lucas 1994; Benner, 1996; Abu-Lughod, 2004). Therefore, women in Islam often face the challenge of deconceptualising Islamist attempts to contain their bodies within rigid sexist structures (Khan, 1998). Abdo (1993) points out that Muslim women are *'silenced, ignored and oppressed, not only by structures and institutions, but also by the social movement, which is derived from its opposition to oppression, namely feminism'* (pg 74).

This view was not only specific to Muslim women; it has been noted in history and other religions. For example, the good Hindu wife should be obedient to her husband (Mace and Mace 1960). Thompson (2005), states that in ancient Greece a woman was always a minor, her consent was not sought and she was obliged to submit to the wishes of her parents when it came to marriage. A woman in ancient Rome was a minor, a person incapable of doing or acting anything according to her own individual taste (The Encyclopaedia Britannica, 1911). Mace and Mace (1960) wrote that in the Christian times, portions of the writings of the Fathers states *'women are represented as the door to hell... as the mother of all ills. She should be ashamed at the very thought that she is a woman... and should live in continual penance because of the curses she has brought to the world'* (pg 80-81).

Cultural practices within the Muslim communities have articulated this belief, although the Quran states otherwise. Chapter four of the Quran is dedicated specifically to women in Islam and provides clear evidence that women are equal to men in the sight of Allah in terms of her rights and responsibilities. The Quran states;

'I will not suffer to be lost the work of any of you whether male or female'

(Al-E-Imran, 3:195, Quran)

Islam gives women equal rights; the automatic right to inheritance, the right to own businesses, the right to choose a husband, the right to divorce, the right to take paid employment, the right to education (Barlas 2002, 139-149) and many other rights that might surprise non-Muslims and sadly, sometimes surprise today's Muslims too. However a recent report by The United Nations Development Fund for Women (UNIFEM) published in 2004 on Arab Muslim women, identifies that Muslim women continue to face gender inequalities in their own homes, and are excluded from opportunities for employment and education. The following verse taken from the Quran may be the reason for such controversies.

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'And they [women] have rights similar to those [of men] over them, and men are a degree above them.' (Al-Baqara, 2:228, Quran)

The statement 'men are a degree above them', has caused many Western societies and Muslims themselves to consider women as people with no rights or say in any activities. This statement in Islamic terms means 'maintenance and protection' (Badawi n.d). This knowing refers to the natural ability and differences in the two sexes. It does not imply any form of superiority or inferiority. The roles of men and women are usually based on their views of the society.

The male bias or superiority occurs by manipulating loopholes in the system to their advantage (Beishan et al 1998). The problem here is not, therefore, the absence of a legal base for women's rights, nor is it because Islam places them in a position inferior to men, and discriminates against them. The real problem lies with a traditional heritage that creates a gender-based unequal situation, and the Western view of Muslim women. For example, a feminist writer Dr. Bronwyn Winter suggests that all monotheistic religions, such as Islam are bad for women, due to pressures placed on them to conform to their societies needs. This is a widely held belief in the West that all Muslim women are oppressed because of their religion. Others however do not portray Muslim women in this sense. Hilsdon and Rozario (2006) state it is no longer a question of oppression, but of women themselves choosing to adopt precisely those Islamic values and practices which are often viewed as backward or oppressive within a Western perspective.

Many younger Muslims across the world, men and women are adopting values and practices that they see as 'Islamic' an increased interest in their religion is part of their attempt to save and protect their religion, and to maintain their identity. An attempt to understand the gender inequality requires a much closer look at the socialisation process of the Muslim culture. Since early childhood, gender roles are clearly delineated. A female is socialised first in preparation for her role as homemaker and mother. The male, on the other hand, is prepared to be the breadwinner. It follows, therefore, that a male's education is favoured over that of the female. A degree of education is necessary for him to get a job whereas in most cases, the degree of education for the female is an additional matter, and not a necessary one. It is important to note here that these are *cultural practices* usually mediated through the Shariah at individual societies level, not Islamic. However

Moghissi (2000) argues that a literal translation of the Quran and the Shariah is incompatible with women:

'...if the Quranic instructions are taken literally, Islamic individuals or societies cannot favour equal rights for women in the family or in certain areas of social life' (pg 141).

Whereas, Wadud (1992) a convert to Islam suggests there are no inequalities within the Islamic framework, noting that the problem is caused by different translations of the Quran. Wadud recommends one must employ the Islamic methodology of *ijtihad* to realise the full potential of Islam, principles of gender equality and social justice (Badran 2001).

What Moghissi (2000) suggests is that some Quranic verses if translated literally do not restrict women excessively although there may be some limitations placed on them. For example, women are free to work outside the house and hold any profession in Islam as long as the sanctity of the family remains intact and a women's honour is not compromised (Al-Musnad 1996, pg 313).

The controversies across the world regarding the role of Muslim women is debated in two ways, firstly by the patriarchal Islamists and patriarchal religious scholars who want to impose their narrow version of religion upon people (divisions of Islam) and secondly by Islamic feminists such as Dr Bronwyn Winter who write off in a single stroke that all monotheistic religions are injurious to ones health. This is similar to religious leaders (scholars) who interpret and preach Islam and Islamic rulings to their own views, for example within the Shafi'i sect women are requested to cover the hair with a headscarf, whereas within the Hanafi sect women must wear the full hijab (Al-Misri and Keller 1994, pg 512-515). Such practices are not determined by the Quran but the teachings and followings of each scholar (refer to figure one, pg 76). This is debated by Dr Bronwyn Winter, *'I can't see anywhere in the Quran where it says...all women must wear the hijab'*, this is because the Quran does NOT state this practice; it is a cultural practice, one that is determined by each Islamic subset.

My attempt in this chapter is not to continue this long held debate, but to enlighten the reader regarding religious issues for Muslim women, following the Quran itself.

Therefore, in terms of religious obligations, women are no different from men, although there are some circumstances where woman are exempt from daily prayers or fasting during her menstrual cycle. Women are also restricted to enter the mosque if they are menstruating, this is due to the belief that the mosque is the holy clean

Wahneema Lubiano (2000) argues that a literal translation of the Quran and the Shari'ah is inappropriate for women.

...In the Quranic tradition, women are taken literally, Islamic individuals or societies cannot have equal rights for women in the family or in certain areas of social life' (pg 147).
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place, and menstruation is unclean. A Muslim woman asked the prophet Muhammed (saw):

'I have children at home, does Allah, still desire for a woman to go to the mosque to perform prayers' the prophet's reply: 'A women should like a man, pray five times daily namaz, for a woman who has young children at home, she by the law of Islam, is able to pray at home'. (Al-Hashimi, 2003, pg 33).

Today this statement by the prophet has caused outrage. A recent documentary based in the North West, showed how Muslim women requested to pray in the mosques, and how the men did not agree to this, stating it was against Islam and that a woman should not enter a mosque. The reason for this can also be found in the Islamic teachings and suggestions made by the prophet himself. The prophet (saw) was once asked by a Muslim woman to be pardoned from attending the mosque to perform prayers, as her children were ill at home. On hearing this, the prophet (saw) stated that:

'A woman does not need to attend the mosque for daily prayers as she may be nursing her baby or caring for the children...but this does not mean that she is pardoned from performing prayers, she should pray at home as this is better for her' (Saleem and Ahad, 2005 pg 183-195).

The media has also placed great emphasis on British Muslim women and the 'Hijab'. The Western view of the hijab or veil is again of oppression, oppression of the Muslim women (Khan 1995); however Papanek (1982) defined the hijab as a 'portable seclusion' in her study in Pakistan. She noted that many saw it as a liberating intervention because it enabled women to move out of segregated living space while still observing the basic moral requirements of separating and protecting women from unrelated men. The hijab is an important aspect of the life of Muslim women, it signifies belonging to a particular community and participating in a moral way of life. There are two types of hijab; external which refers to clothes, and internal, which refers to attitudes and behaviour (Khattab 2001).

There is no Islamic law on women's dress code however, cultural obligations are apparent. Two such obligations were found:

- The definitions of the Islamic dress consist of the covering of the whole head and body, except the face or hands.

place, and men and women are not equal. The women are not equal to the men, and men are not equal to women.

I have written a book about this. It is called 'The Women of the Middle East'.

Today the situation is very different. The women are not equal to the men, and men are not equal to women.

There is a lot of talk about the rights of women. But what are the rights of women?

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- The clothes should be thick enough to conceal the colour of the woman's skin and the shape of the body ¹⁴(Khattab, 2001, pg 15-19).

Different Islamic scholars have had much say about the dress code of Muslim women. Shafi and Hanbali sects favour the covering of the face and hands. The Maliki and Hanifi consider the whole body should be covered except the face and hands. This suggests the dress code for women in Islamic societies is determined by cultural preferences, and is not specified in Islam itself. This tradition has been continued in today's Western society, and is considered a sense of belonging and identity. According to Abu-Lughod (2002) people wear the appropriate form of dress for their social communities and are guided by socially shared standards, religious beliefs, and moral ideals, unless they deliberately transgress to make a point or are unable to afford proper cover. The dress code is just one part of the hijab of being a Muslim woman, the second is the internal hijab, which has rarely been considered by many authors as important.

The internal form of hijab was expressed thus by the prophet Muhammad (saw):

'Modesty, shyness and bashfulness all constitutes woman's attire'

(Khattab 2001, pg 18).

Fatimah (1996) defines modesty in Islam as freedom from vanity and showiness, which includes language, dress and attitude. The value of modesty is regarded as a must in Islam by both sexes. A verse in the Hadith identifies the importance of modesty:

'Every religion has a character and the character of Islam is Modesty' (Fitzgerald et al, 2006, pg 33).

The view that all Muslim women are oppressed, or that Muslim women who decide to wear the hijab have no freedom needs to be removed, from both the Western societies thoughts and the thoughts of Muslim men themselves. The Quran identifies that both sexes are equal, gender differences have become common place due to cultural practices that have continued for generations and not prescribed in the holy texts.

¹⁴ The Quran simply says that women should dress modestly, but it does not define what this means. Some cultures have interpreted this rigidly, insisting that women should cover themselves from head to toe in hijabs, while others only require head scarves.

* The clothes should be thick enough to conceal the colour of the woman's skin and the shape of the body" (Khatib, 2001, pg 15-16).

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¹⁰ The Quran simply says that women should dress modestly, but it does not define what this means. Some cultures have interpreted this rightly, insisting that women should cover themselves from head to toe in hijab, while others have rejected headscarves.

It is a cultural belief that members of the opposite sex should avoid eye contact for reasons of modesty and respect. Whether a Muslim woman wears a hijab or not she should still strive to adopt Islamic behaviour. Some scholars have stated that women should not talk to men whom they are not related to, as it may be attractive to men, however others scholars disagree (Al-Misri and Keller, 1994 pg 510-514).

For British born or for those Muslim women who work outside the house, talking to men to whom they are not related can be quite difficult. In our daily conversation, communication with the opposite sex cannot be avoided, especially if a Muslim woman seeks education or employment. The mixing of men and women is another conflicting area. Some scholars disagree with this whilst others permit it (Al-Musnad 1996, pg 373). Living in any Western society, this cannot be avoided. Touch is another act, which is strictly prohibited between members of the opposite sex, even shaking hands (Al-Musnad 1996, pg 373). In British society, the 'hand-shake' is a sign of politeness to greet somebody, which cannot be avoided unless all contact with the outside world is avoided all together. These thoughts are especially challenging for Muslims born outside the Islamic countries.

There is a lot of literature surrounding women in Islam that claims to state what constitutes lawful and unlawful acts¹⁵. It is impossible to cover all the aspects of women in Islam in this short chapter.

I would like to conclude by stating that nowhere in the Islamic law has it been suggested that a woman is a minor simply because she is female. Islam notices the vital role of a Muslim woman as a mother and a wife as the most sacred and essential one. This does not suggest women are second-class citizens nor that they have no rights. Some writers have unfairly exaggerated some deviations, and the worst of this, in a superficial way, been taken to represent the teachings of 'Islam' to the Western reader. Such writers and commentators have not taken the trouble to make any original and unbiased study of the authentic source.

The following section will consider health, illness, disease and wellbeing in the Islamic perspective and how it influences Muslims.

¹⁵ Books on women in Islam include: Islamic Fatwa regarding women. The ideal Muslimah; Believing women in Islam reading patriarchal interpretations of the Quran. These three books are the ones I have referred to mainly.

Health within the Islamic framework

The Quran considers 'Iman', faith in Allah, as the foremost necessity for spiritual and mental health and stability. Illness and well-being are closely connected to Islam by every Muslim in believing and understanding that suffering and dying are a part of life and a test from Allah:

'Be sure we shall test you with something of fear, hunger, some loss of wealth, lives or the produce (of your toil), but give glad tidings to those patiently persevere' (Al-Baqarah, 2: 155. Quran).

From an Islamic perspective, health is viewed as one of the greatest blessings that God has bestowed on humankind. Indeed, it should be noted that the greatest blessing after belief is health. The prophet (saw) states:

'Ask Allah for forgiveness and health, for after being granted certainty, one is given nothing better than health.' (Majlisi et al 2007, pg 137).

An individual's understanding of concepts such as 'health' and 'disease' arise from a complex interaction between personal experiences and a range of cultural factors that may include, among other things, language, family values and norms, and religion (Helman 2001). These factors are of great importance in determining one's outlook on health and life in general. In communities such as the Muslim society where they retain a sense of the sacred, the influence of religion on shaping the individual and communal view is often quite considerable (Rahman, 1998). This does influence beliefs about ill health and well-being, and is likely to be strong.

The general belief of Muslims is that cure comes solely from 'Allah'. Even if this is practically in the form of a health professional, it is still ultimately achieved through prayers.

Illness has three possible meanings in Islam, 'a natural occurrence', 'punishment of sin', or 'a test of the believer's patience and gratitude' (Ibn Musa 1982). Regardless of the cause, it is obligatory for the sufferer to seek treatment. The prophet (saw) states:

'For every illness, there is a cure, except death'. (Al-Misri and Keller, 1994, pg 188-189).

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Islam places considerable emphasis on health and prevention. The health of the Muslim is very important, as the healthier the Muslim is the more they worship Allah. Health in Islam is built on a hygienic regime, which creates a community that is healthy and immune against disease (Al-Fangary n.d). This is known as ablution (wadu). The Quran itself is described as a cure. The prophet Muhammad (saw) states in the Hadith:

'Allah did not reveal any disease, without revealing its cure, some people may know the cure and others may ignore it but it nevertheless exists'.

The five pillars of Islam as stated above (pg 67) are prescribed as spiritual health, and also physical health. The ritual of wadu is highly recommended. Cleansing of certain body parts prior to performing prayers helps to maintain a clean body. The light but constant movements in namaz are also known to maintain physical as well as spiritual growth, to name a few.

Prescribed by the prophet Muhammad (saw)

The prophet's definition of health is the opening of Hadith, which is as follows:

'O, person waking up for his day, then finds himself and his family and the surrounding community in a secure, safe and peaceful state (of mind); that he is fit in his body; and that he is possessing enough provisions of eatables for his daily living; he is then as if all the precious contents of the whole world have been bestowed upon him' (Hussein n.d)

One of the principles of the Islamic health care is to prevent suffering and disease prior to any clinical manifestations (Al-Misri and Keller, pg 966-990). The entire life is guided and directed towards wholesomeness and longevity with the emphasis on prevention. Islam as an ethical and holistic way of life deals with the spiritual and physical aspects of an individual's life. The Hadith provides a description of the Prophet's daily routine and as a prototype for Muslims that will give an idea about the kind of healthy living and preventative dimensions of health, illness and disease.

How does Islam affect Muslims seeking health care?

There are no statements in the Quran or Hadith, which prevent Muslims from seeking help from physicians or practitioners. Seeking health care is in fact encouraged in Islam. The Quran states that individuals should not be arrogant by the fact that cure

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is only sent from Allah, but in some cases that cure operates through other humans, and that this does not contradict the belief in Allah.

Religious cognitions and behaviours, especially those centring on prayers, meditation, and other devotional pursuits, seem to be valuable in dealing with serious health problems and bereavement, within the Muslim communities. People tend to turn to Imams, Hakims or Peer Saab for guidance, who play a role in the cure of disease, through passages from the Quran or Hadith.

Some studies have focused on South Asian women's cultural beliefs and values related to health care (Bhopal 1986, Bhagat et al 1995, Sodhi 1995, Dhari et al 1997).

These studies suggest that family structures, traditional behaviours, norms regarding appropriate behaviour for women, and modesty surrounding health concerns that are particular to women's attitudes about illness have a profound affect upon the health choices made by the members of this group.

Gender of the health care professional

Gender issues, and in particular the rights of women in Muslim culture, continue to generate much media attention in the West (Dhami and Sheikh 2000). Muslim etiquette demands that women should not expose certain bodily parts to anyone except their husbands. This has caused many problems for Muslim women who have become reluctant to attend for gynaecological examinations due to the fear of what religion demands or forbids. According to the Quran, women are not restricted from seeking health care from a male professional, even if it requires examination.

According to the Hadith, a woman should follow the criteria when seeking health care:

'A woman needing medical attention must be treated by a Muslim doctor'

If one is not available then the following steps are necessary to follow for treatment:

- a. *'A non Muslim woman doctor... then*
- b. *'A male Muslim doctor... FINALLY*
- c. *'A male non-Muslim doctor' (Al-Misri and Keller, 1994, pg 514).*

This tenet of Islam is further elaborated by the fact that *'if the doctor is of the opposite sex, her husband or an unmarriageable male relative must be present'*; this is obligatory for both males and females in Islam (Al-Misri and Keller, 1994, pg 514).

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It is evident that cultural beliefs are so closely related to religious ones that people appear to be unable to distinguish between the two (discussed in chapter 12 pg 209-226).

Modest dress is incumbent on all Muslim's on reaching the onset of maturity. Religious and cultural beliefs, such as the value placed on modesty and premarital virginity, contribute to reluctance to seek health care (Matin and LeBaron, 2004). This is one area that has been identified through the literature that seems to have caused conflict in the health care system, where professionals are unable to provide care for Muslim patients (Al-Azhary Sonbol, 2003, pg 220; Sheikh and Gatrad, 2007, pg 59). In addition, where patients have felt neglected or discriminated against due to their religious beliefs and practices, (Marwa 2000, Advani et al 2003; Baral et al 2007; GMC 2008). Bhakta et al (1995) found in their studies of Asian women and breast screening that this group did not perceive themselves as being at risk, and often stated feelings of shyness on being examined by a male practitioner. This was also identified by Day (1994) who states there is importance placed on the preservation of women's dignity in South Asian communities, resulting in hesitancy to be touched by a male doctor or to un-robe for examinations.

This hesitancy can also be related to the religious tenets that state:

'A man may look at his wife including her nakedness, though it is offensive for either husband or wife to look at the other's genitals' (Al-Misri and Keller, 1994, pg 512)

Physical contact between members of the opposite sex is strongly discouraged in the Muslim culture and religion, which explains why many women prefer to see a same-sex doctor particularly where examination of the genitals is required.

Communication

Poor communication and a lack of appropriate resources and literature are all areas of concern (Hawthorne, 1994). Communication and language barriers have been reported frequently in research as a form of barrier for the ethnic minority populations. Rankin and Bhopal (2001) undertook a cross-sectional survey of South Asian people living in South Tyneside (UK), in 1996 to assess the understanding of heart disease and diabetes. Rankin and Bhopal (2001) found that out of a sample size of 334 participants, 92 (28%) did not understand the meaning of the term diabetes, a further 43 (13%) could not provide a description; 75 (22%) were unable to suggest any risk factors; and 64 (20%) could not give a preventative measure. These

figures published by Rankin and Bhopal (2001) clearly state that there is a major, urgent need for education within the South Asian communities on the causes and prevention of diabetes and other disease.

Many research articles that are based on communication are specific to the ethnic minority population and the need to provide this group with educational material. However, as Marwa (2000) stated, sometimes the educational materials available are too simplistic, or the language level too complex to be helpful, or they only relate to the cultures of countries of origin and not to the contemporary issues of British ethnic minorities. Greenhalgh (1997) found that knowledge, health beliefs and attitudes to illnesses was lacking by the ethnic minority population as a whole. Therefore providing visual representation for example, posters and other health care materials in other languages may be of benefit.

There is also evidence that suggests the ability to speak English is lower in women than men, and is much poorer for those born outside the United Kingdom (Rudat, 1996). Literacy is another factor. Although people may be able to speak English, they may not be able to read it. Further, even if information is translated, people may not be able to read their own languages. There may not even be an agreed written format.

For this reason, many people from the ethnic minority groups tend to consult professionals who are able to speak their language (Johnson et al, 2004, MacDonald 2004, Milne 2005, Stewart 2005, Johnstone and Kanitsaki 2006). Although being able to speak a patient's language is essential, it does not always guarantee effective communication between the client and the provider.

Muslims' understanding of Illness

It is increasingly clear that specific attributions or causal explanations can be fully understood only by taking into account the wider belief and value system of the individual. People from different cultures often make very different attributions, make attributions in different ways or approach the entire task of social explanations in different ways (Triandis 1976; Bond and Smith, 1996; Markus et al, 1996).

According to Rassool (2000) Muslims believe an illness is not something viewed in the negative sense, but rather as a positive event that purifies the body, which is narrated by the prophet in the Hadith as '*the prayer of the sick person will never be rejected, until he recovers*'. (Rassool 2000).

However, seeking treatment for ill health does NOT conflict with seeking help from Allah. The prophet (saw) states:

'God has given you knowledge to elevate illness. Allah gives you an illness, but Allah also sends you a cure, whether be it through a doctor, Peer Saab, religious practices, or prayers'. (Al-Misri and Keller, 1994, pg 13).

For this reason many Muslims do not seek help, as they believe illness can and will purify the body. This is also found by Rassool (2000). Research has identified that some Muslims do not comply with medical treatments (Bashir et al 2001; Heath, 2003; Khokhar et al 2008). This may be because some medications contain pork extracts, alcohol or liquor that is strictly forbidden in the Islamic religion.

Possession of the soul

The concepts of 'evil eye' and 'spirit possession' are reported in so many cultures that they may be regarded as a universal phenomenon (Spooner, 2004). According to Friedman and Walter (2004) evil eye represents a fear of evil influence through other people, an act of jealousy and envy. The Asian term for evil eye is 'nazar', however this is not actually mentioned anywhere in the Quran. The fourth pillar of Islam, the duty of zakat is commonly believed to remove the evil eye (Musk 2004), and for this reason, many Muslims across the world continue this practice. Spirit possession on the other hand refers to the belief that a spirit can enter a living person, possess them, and control what they say and do. The belief in 'spirit possession' or 'evil eye' is common within the Asian culture/communities, particularly for the Western diagnosis of depression and psychological illness. Depression is not a term found in Muslim cultures. It is common for people to state 'the person's soul has been possessed, by bad spirit'. The idea of another person making someone ill by the use of 'witchcraft or voodoo' is common. These two concepts of 'soul possession' and 'witchcraft' should be considered when understanding the influence of culture on health, as Asian communities in the United Kingdom strongly believe that this affects their health.

Health professionals' views of people from other cultures

Health professionals today face the challenge of caring for patients from many cultures who have different languages, levels of acculturation, socio-economic status, and unique ways of understanding illness and health care.

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Health professionals' views of people from other cultures

Health professionals today face the challenge of caring for patients from many cultures who have different languages, levels of education, socio-economic status, and unique ways of understanding illness and health care.

Attempts to educate professionals tend to rely heavily on categorical constructs that 'lump' patients of similar cultures into groups with 'characteristic' values, customs and beliefs (Spector 1992, Harwood 1981). This suggests that people who identify themselves through specific religions, or have similar characteristics, have the same views, which is a dangerous thought. Having the same characteristics, for example, brown skin, blonde hair, blue eyes, tall etc, does not determine everyone will behave the same and have the same value system. Cultures all have their sub-groups, and these are not simply defined by ethnicity. According to Gerrish et al (1996) health professionals' understanding of other cultures remains poor, although there is increased diversity in the percentage of ethnic minority populations in the UK.

Health care professionals may have strong stereotypical views, lack cultural awareness and ability, or generally manage patients from diverse backgrounds in an unsuitable manner, which creates barriers and sometimes resentment. This is not only relevant to health care professionals but also patients who access services.

Summary

In this chapter I have drawn upon the Muslim way of life, Islam, as a religion, and Islam as a culture. In the Muslim world, there is an increasing recognition of the need to distinguish between cultural traditions, which may have nothing to do with Islam, and the true teachings of Islam. The cultural fabric of the Muslim community according to Raza (1991) reveals an intricate web. Some of the factors are barriers for the Muslim community, including the areas of social, economic, and health care. Many cultural factors and beliefs have been brought from the country of origin with migrant communities. National culture traits, norms, and customs therefore have to be carefully distinguished from Islamic culture.

Sometimes, such cultural beliefs can dominate more than the religion itself. Cultural practices of Muslim communities are strong and very closely linked to their religious beliefs. Religion has a major influence on the way in which Muslims view and understand their lives. The problem arises when people confuse religious practices with culture.

As societies become more diverse, it is increasingly important to emphasise the need to provide services for the particular needs and requirements of the individual patient not only in relation to their clinical needs, but also in relation to their cultural, religious and spiritual needs.

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Illness is viewed within the Islamic perspective as a way of cleansing the soul, and is usually received with open arms. Many Muslims will therefore delay seeking help, which can sometimes increase the severity of their symptoms. Gender issues, communication, segregation of the opposite sex, and modesty have all been addressed in this chapter as cultural barriers that can prevent Muslim women seeking health care. Religiously in Islam, no such restrictions are placed on women or men. This suggests that these are culturally driven views and practices. Whether cultural or religious, they make up the identity of the Muslim communities.

The next chapter will draw together the literature review chapters to provide a summary of issues that have been identified.

Conclusion drawn from the literature review

The previous three chapters have provided the background literature that is the base for this study. Studies examining risk factors for developing UI in women have shown a positive link between a range of factors. Age is the most cited risk factor (Milsom, 2000; Gray, 2003, Nelson and Furner 2005), due to changes in the pelvic floor muscles at later age. Vaginal childbirth is also another commonly reported risk factor for UI in women, due to obstetric trauma (Hojberg et al 1999; Buchsbaum et al 2002; Sze et al 2002; Waetjen et al 2007; Tennstedt et al 2008). Race as a risk factor for developing UI is questionable, but has been cited by some authors.

Urinary incontinence is a subject which is widely researched within the White majority of the population. It is without doubt that the psychological impact of UI is similar across all ethnic groups. However, viewing leaking urine within the context of religion and culturally orientated practices will inevitably raise unique issues. The affect of UI on quality of life has been reported to have a detrimental affect on some sufferer's lives. However the perception of quality of life very much depends on the individual's interpretation of what this term means, and their understanding of it (Edlund and Toncredi, 1985), and their preferences and priorities in life.

Previous research has shown that many sufferers have learnt to accept the problem and feel it to be a natural corollary of old age. Urinary incontinence is not seen as an illness or disease, and many individuals learn to live or self-manage their symptoms, and to cope reasonably well.

The decision to engage in any health care activity is influenced by many factors including gender, age, social status, the type of illness, knowledge, access to services, previous experiences and the quality of the service, and encouragement of significant others (Tipping & Segall, 1995). Many sufferers of UI prefer not to mention their incontinence to others, and so the opportunity for others to encourage them to seek help does not arise. Personal and social attitudes towards incontinence can also hinder many seeking help. This relates to the historical stigma attached to this condition. Low levels of access to UI services are apparent within the literature (Jolleys, 1988; O'Brien et al, 1991; Brocklehurst, 1993; Harrison & Memel, 1994).

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appropriate. As Kleinman (1980) and Young (1982) state, these models are not adapted for the real people, and how they experience illness, wellness and disease. What these models appear to do is disengage the inter-subjective experiences that individuals assign to any conditions, as emotions are seen as socially disabling. Further, and most importantly, these models have not been applied to groups that are religiously based, and who view conditions of illness and health to be the blessings of their God.

The inability to directly communicate with professionals due to language barriers and beliefs can also restrain people from seeking help. The subject of UI is sensitive in its own right. However if an individual decides to seek help due to the severity of UI, the problem becomes even more difficult if the individual cannot communicate independently in English. Poor communication can lead to non-compliance and non-attendance. Even if they decide to seek help, previous research has found that non-English speaking patients find health professionals spend less time with them because they cannot communicate easily with them (Henley and Schott, 1999), which effects the quality of care provided. The lack of ability to communicate directly with health care professionals leads many to rely on relatives rather than trained interpreters, which again can cause further problems.

Research into women suggests that the affect of UI on daily activities and social life may vary by the type of incontinence and may be independent of the severity of UI (Ashworth & Hagan, 1993; Gray, 2003). The more severe the leakage the more likely is the individual to seek help (Shaw 1999). One of the goals of the present study is to broaden our understanding of the factors associated with Muslim women when considering seeking help for urinary incontinence, and what urinary incontinence means to this group.

In the next chapter, I will situate my study within a social constructionist view and draw upon a hermeneutic phenomenological approach to guide the study.

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Chapter 3

Hermeneutic Phenomenology

The previous chapters concentrated on the literature review in support of the research aim. While there is a wide area of literature on specific health conditions in relation to the Muslim communities, it is apparent that the perceptions and beliefs of Muslim women around urinary incontinence have not been fully explored.

Introduction

In this chapter the theoretical approach to this study is considered. I outline why a hermeneutic phenomenological approach was chosen over other approaches, based on the nature of the research. The chapter is organised into two distinct sections. The first section describes the epistemological perspectives of the study, with an overview of the three main approaches to social science, objectivism, subjectivism and social constructionism. Following on from this I will distinguish why I choose a social constructionist view.

In section two I have addressed the theoretical perspectives. Within an interpretivist approach that I have taken I will outline a further three methodologies that are linked with this school of thought, that search for meanings and interpretations. The three methodologies that are discussed will be ethnography, phenomenology and hermeneutics.

As I have taken a hermeneutic approach the final section of this chapter will then only consider this approach in more detail with regard to the historical origins and the two main pioneers, Martin Heidegger and Hans Georg Gadamer.

Qualitative research verses Quantitative research

Research has primarily been divided by ideologies, paradigms, perspectives, and epistemological positions, qualitative inquiry or quantitative inquiry that determines the data collection methods.

Qualitative inquiry describes theoretical perspectives/approaches such as ethnography, naturalistic, anthropology, and phenomenology (Polit and Beck 2004, pg 15). These approaches attempt to describe and interpret some human

Introduction

In this chapter the theoretical and methodological foundations of hermeneutic phenomenology are explored. The chapter is organized into three main sections. The first section describes the philosophical roots of hermeneutic phenomenology. The second section discusses the methodological foundations of hermeneutic phenomenology. The third section discusses the application of hermeneutic phenomenology to management research.

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Qualitative research is a research approach that seeks to understand the meaning and experience of human beings. Research has primarily been conducted by researchers who are interested in understanding the meaning and experience of human beings. Research has primarily been conducted by researchers who are interested in understanding the meaning and experience of human beings.

Qualitative inquiry uses a variety of methods to collect and analyze data. These methods include interviews, focus groups, and ethnography. These methods are used to collect and analyze data. These methods are used to collect and analyze data.

phenomenon, usually through words or narratives of those subjects and by direct observations of the phenomenon. These perspectives usually fall within an interpretivist paradigm. Quantitative researchers on the other hand attempt to gather data by objective methods, which involve the collecting of the data in the form of numbers, which can be measured so it is measurable by nature. This type of research is based on the empirical evidence and aims to describe, explain and predict (Black, 1999). The approach for quantitative inquiry is determined by positivism and logical empiricism. This perspective removes the investigator from the investigation and identifies pre-determined variables which are to be measured and assessed (Parahoo, 1997).

A central methodological issue for positivist research is the reliability and the representativeness of the sample. For the qualitative approach 'authenticity' rather than reliability is often the issue. The aim is usually to gather an 'authentic' understanding of peoples' experiences. Guba and Lincoln (1989) describe authenticity as a way to demonstrate if researchers can show that they have represented a range of different realities, including fairness, sophistication, mutual understanding, and empowerment (pg 248-251). These issues will be used as a guide to ensure authenticity within this project and are discussed in more depth in chapter four.

There are clear distinctions between these two approaches to social science, which guide the epistemology, theoretical approaches and the methods applied to the study. The following section will discuss the distinctions in relation to the epistemological and theoretical stance, focusing on how they apply to this study and how it aligns with social sciences paradigms.

Aim and sub-aims of the study

To understand how I came to adopt a social constructionist epistemological position and the theoretical perspective of a hermeneutic phenomenology, the aim(s) of the study need to be reconsidered. According to Cohen et al (2000) the research design should match the question asked (pg 3). This study intended to explore the religious and cultural influences on help-seeking behaviour in South Asian Muslim women with urinary incontinence.

Within the overall aim, specific sub-aims were developed:

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Within the overall aim, specific sub-aims were developed:

1. To explore beliefs about urinary incontinence amongst these women.
2. To examine the relationship between the severity of the condition and help-seeking behaviour.
3. To understand help-seeking behaviour and decision-making among women who have received health care from continence services and women who have not received services for urinary incontinence.

Following the aims of this study, the qualitative approach is considered appropriate, with the aim of interpreting phenomena. Further, I have considered three approaches that can be applied to a study of this nature.

The following section will however start at the beginning of any research project to determine the three main epistemological positions that would need to be considered.

Epistemology: 'what we know' and 'how we know'

Epistemology, or the theory of knowledge, is driven by three main questions: 'What is knowledge?' 'What can we know?' and 'How do we know what we do know?' (Greco and Sosa 1999). Throughout the history of philosophy, these questions have caused intense debates and they have generated a number of epistemological positions in order to answer such questions.

Firstly, I will consider 'objectivism' as an epistemology, followed by 'subjectivism' and finally 'constructionism'. Figure two summarises the school of thought behind each epistemological perspective.

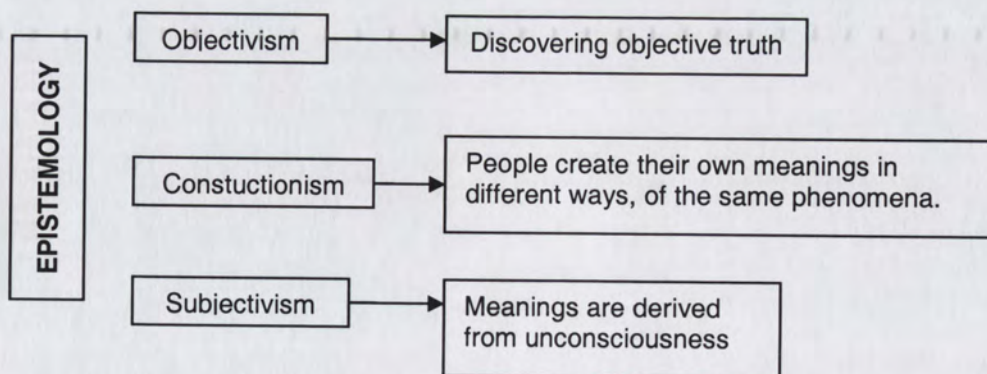


Figure 2 Three Epistemological Perspectives adapted from Gray (2004 pg, 30).

1. To explore the relationship between the two variables.
2. To examine the relationship between the two variables.
3. To understand the relationship between the two variables.

Following the same line of thought, the author suggests that the relationship between the two variables is not only a matter of fact but also a matter of value. That is, the relationship between the two variables is not only a matter of fact but also a matter of value.

The following section will discuss the relationship between the two variables. The first part of the section will discuss the relationship between the two variables. The second part of the section will discuss the relationship between the two variables.

Epistemology, what we know, and how we know it. Epistemology is the study of knowledge. It is the study of the nature of knowledge, the sources of knowledge, and the methods of knowledge.

Knowledge is the body of information that we have about the world. It is the collection of facts, ideas, and experiences that we have gathered over time. Knowledge is the foundation of all human activity.

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Figure 1 The relationship between Epistemology, Ontology, and Ethics

In the following section, I will describe each perspective, in relation to the study aim(s). I will then describe why I take a 'constructionist' view rather than subjectivist or objectivist epistemological position.

Objectivism, Subjectivism verses Social Constructionism

An objectivist epistemological view according to Crotty (2003) holds that *'meanings and meaningful reality exists apart from the operation of any consciousness'* (p.8).

A summary of the purpose of objectivism is described as follows:

'Reality, the external world, exists independent of man's consciousness, independent of any observer's knowledge, beliefs, feelings, desires or fears. This means that A is A, that facts are facts, that things are what they are, and the task of man's consciousness is to perceive reality, not to create or invent it' (Binswanger and Peikoff, 1990, pg 40).

According to this view, objects have fundamental meaning and knowledge is a reflection of the reality, which can only be gained through experimentation (Crotty, 2003 pg 5-6). According to Rand (1966) concepts and values are not fundamental to external reality, nor are they subjective, but objective. Objectivist epistemology views *'that things exist as meaningful entities independently of consciousness and experience, that they have truth and meaning residing in them as objects'* (Crotty, 2003, pg 5). The belief that human experiences play a minor role in structuring the world is deep-seated in this approach, *'meanings are something that exists in the world quite aside from experience'* (Duffy and Jonassen 1992, pg 2). Knowledge represents a real world that exists separate and independent of the knower (Boghossian 2006) and is considered as truth. Objectivism as a theory focuses on what we see around us is real (Becvar and Becvar 2003), and individuals and behaviour can be objectively studied.

By using such logical and objective methods of science, a reality, a truth, an objective world, independent of our thinking, can be discovered. However, Kratochwil and Ruggie (1986) argue that *'norms and regimes cannot be studied positivistically but have to be seen as inter-subjective phenomenon only researched by non-positivist approaches'*. This study is concerned with values, beliefs and practices in the Muslim communities. Therefore, within the research question I pose the exploration of practices, values and beliefs within this study group would not be possible. Whilst

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previous research on urinary incontinence has largely been based on predictors, drawing on categorisation and treatment of related conditions of the sufferers, they do not explore situated experiential meanings within the population group. Within this approach, the narrative world of the individual would be considered of little value in understanding their experiences.

At the opposite end of the epistemological continuum, there is subjectivism. This perspective rejects the view of objectivism. According to Lane and Ersson (2003) subjectivism as an epistemological stance rejects the notion of shared culture values, and does not address socialisation aspects in terms of influencing meanings. This view holds that individuals do not need to concern themselves with the facts of reality, instead they arrive at knowledge or truth through the feelings attached to it. According to Peikoff (1995) subjectivism is the doctrine that feelings are the creator of facts, and therefore becomes the primary tool of cognition. According to Ayn Rand reality within this belief is not absolute, but a fluid, plastic indeterminate realm which can be altered, in whole or part, by the consciousness of the perceiver, his feelings, wishes or whatever (Tymieniecka, 1991 pg 124).

Subjectivity has been referred to as not simply a passive relationship to the world and the sense impressions it causes subjects, but also an active engagement with that material (Crotty, 2003 pg 9). This may be thought to occur simply in the act of interpreting sense data, making choices and assigning meanings to the data.

Subjectivism then as an epistemological stance accords primacy to the subjective experiences of those studied. In an extreme form, it may hold that the nature and existence of every object depends only on someone's subjective awareness of it (Gray 2004 p.17). Within this approach to social science a distinction exists between the researcher [subject] and the participants [objects].

This theory relates to analysing terms or words, and refers to a particular location of the event (Crotty 2003). According to Gunning (2004) subjectivists are not directly interested in an individual's behaviour, as we observe or measure it. The behaviour must be conceived through the eyes and the mind of the person. This theory holds that knowledge is generated from the mind, without reference to reality. The world becomes a figment of our imaginations. Subjectivism claims that the mind controls particular aspects of reality, or that certain facts of reality don't exist and can be whatever the mind wants. In relation to the research question then a subjectivist stance would not be suited, as religion became an influential factor in the lives of the

previous research on whistly incontinence has largely been based on predictors, drawing on categorisation and treatment of related conditions of the sufferer, they do not explore situated experiential realities within the population group. Within this approach, the narrative world of the individual would be considered of little value in understanding their experiences.

At the opposite end of the epistemological continuum, there is subjectivism. This perspective rejects the view of objectivism. According to Lane and Eason (2003) subjectivism as an epistemological stance rejects the notion of shared culture values, and does not address socialisation aspects in terms of influencing meanings. This view holds that individuals do not need to concern themselves with the facts of reality, instead they arrive at knowledge or truth through the feelings attached to it. According to Peckoff (1995) subjectivism is the doctrine that feelings are the creator of facts, and therefore become the primary tool of cognition. According to Ayn Rand, reality within this belief is not absolute, but a fluid, plastic indeterministic realm which can be altered, in whole or part, by the consciousness of the perceiver, his feelings, wishes or whatever (Tyminski, 1991 pg 124).

Subjectivity has been referred to as not simply a passive relationship to the word and the senses impressions it causes subjects, but also an active engagement with that material (Crotty, 2003 pg 8). This may be thought to occur simply in the act of interpreting sense data, making choices and assigning meanings to the data. Subjectivism then as an epistemological stance accords primacy to the subjective experiences of those studied. In an extreme form, it may hold that the nature and existence of every object depends only on someone's subjective awareness of it (Gray 2004 p.17). Within this approach to social science a distinction exists between the researcher (subject) and the participants (object).

This theory relates to analysing forms or words, and refers to a particular location of the event (Gray 2003). According to Gunning (2004) subjectivists are not directly interested in an individual's behaviour, as we observe or measure it. The behaviour must be conceived through the eyes and the mind of the person. This theory holds that knowledge is generated from the mind, without reference to reality. The world becomes a figment of our imagination. Subjectivism claims that the mind controls particular aspects of reality, or that certain facts of reality don't exist and can be whatever the mind wants. In relation to the research question then a subjectivist stance would not be suited, as religion became an influential factor in the lives of the

participants. Whereas within this view of subjectivism ethics are not consider therefore the participant will act in any way they choose without consequences.

A subjectivist approach would be that there is no absolute standard against which a person's preferences can be measured, therefore whatever someone believes is right (Porter 2001, pg, 70). Importantly in this research question, I am interested in exploring the affect of religion and culture on Muslim women's lives. This approach may be impossible as it rejects the view that shared views influence behaviour or meanings.

The constructionism or social constructionism epistemological approach falls between the above two approaches. It rejects the views of objectivism and subjectivism (Crotty, 2003). Truth and meaning are situated in the experiences of the individual. For example, the perceptions and experiences of leaking urine become 'truthful'¹⁶ to those women experiencing them, it is the way they construct the meaning of leaking urine in their life. The belief or the meaning is shaped by social forces, and there is no obvious fact.

There are no such things as facts within a social constructionist view; therefore all knowledge is derived from looking at the world from some perspective (Burr 2003, pg 6). Our understanding of the world is not influenced by objective reality but the interplay with other people, both past and present. We are born into a culture, a society that already exists. So for example, when referring back to the study aims, Muslim women may refer to the cultural knowledge of how to behave as a woman, which may influence the way they view themselves, leaking urine or seeking health care. This is only possible through the use of language. Indeed Burr describes the way a person thinks about a given phenomenon is provided through the concepts and categories of language (Burr 2003, pg 8).

People construct meanings in different ways, for example, what one may feel about a given situation the other will not necessarily feel the same (Gray 2004). In relation to the aims of the current study, what some Muslim women may feel and experience in relation to leaking urine or seeking health care, may not be similar to those

¹⁶ By truthful I am not referring to an objective truth, what I am referring to is the meaning that people assign to events or phenomena, which will be different for all, although it will be true to that person experiencing it.

participants. Whereas, when the new 10-item scale was used, the mean score for the entire sample was 1.5 (SD = 0.5).

A subject's degree of awareness of the meaning of the word "rape" was assessed by asking the subject to write down the meaning of the word "rape" in his or her own words. The subject's response was then compared to the definition of "rape" in the dictionary. The subject's response was considered correct if it contained the words "sexual intercourse" and "without consent".

The construction of a new 10-item scale was based on the results of the factor analysis. The new scale was constructed by selecting the items that loaded on the factor that represented the construct of "awareness of the meaning of the word 'rape'". The new scale was then tested on a sample of 100 college students. The results of the factor analysis showed that the new scale had a Cronbach's alpha of 0.85, indicating good internal consistency.

There are no other studies that have used a scale to measure awareness of the meaning of the word "rape". The results of the present study suggest that the new 10-item scale is a valid and reliable measure of awareness of the meaning of the word "rape". The scale was found to have good internal consistency and to be able to distinguish between subjects who were aware of the meaning of the word "rape" and those who were not. The scale was also found to be a good measure of awareness of the meaning of the word "rape" in a sample of college students.

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People construct their own meaning: My Epistemological Stance

Previous research has identified many factors that either contribute to UI or are significant to this problem (examples of the research include Horsfield 1986, Breakwell and Walder 1988, Bump 1993, Grimby et al 1993, Herzog et al 1994, Castro-Diaz et al 2006). These factors include age, gender, vaginal childbirth, multiple childbirth, other illnesses i.e. stroke, diabetes and asthma. Many sufferers of UI conceal their problem due to embarrassment and shame (Norton 1982; Wyman et al 1987; Norton et al 1988; Bjurbrant-birgersson et al 1993; Fillingham and Douglas, 1997). Others have often concealed their problem and isolated themselves within their own homes (Ouslander & Abelson, 1990; Lagro-Janssen et al, 1992; Brocklehurst, 1993). One study identified that Muslim women felt devastated due to leaking urine as the disruption of leaking urine whilst performing prayers formed a barrier between the performer and their God (Chaliha & Stanton, 1999), as praying is seen as a relationship between the two (Al-Misri and Keller, 1994), and UI disrupted this relationship.

The type of knowledge required to answer the question indicates that the epistemological position underpinning the study will be that of constructionism rather than an objectivist or subjectivist view. Constructionists argue that almost everything in the social world is socially created (Crotty, 2003) differing only in the way the study is conducted and the findings analysed. For example taking an ethnographic approach would suggest participant observation as a data collection method.

Objectivist approaches to research are helpful where there is an existing theory, or where such data are collected simultaneously, as in those studies that have validated tools. Taking this approach would mean that I believe that the social world can be studied objectively, that it can be broken down into separate entities and measured, that it can be described and discovered without any influence from the researcher. However, I would argue that the situation of Muslim women who deal with leaking urine on a daily basis is so complex with confounding factors that are not receptive to being measured in any meaningful way. Many of the confounding factors include 'religion' 'religious practices' and religion as a 'referential framework for their

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behaviour'. Also I do not believe data could be studied objectively by me as I follow the same religion, and it is part of my way of being in the world.

Therefore, my standpoint is in line with that of social constructionism as it states that knowledge is not 'out there' to be known, rather how we know the world is through interplay of cultural and social factors. Also we can never operate outside our understanding of the world. Hence, reality is constructed through a person's active experience of it.

Within the concept of constructionism, then, *'all knowledge, and therefore all meaningful reality as such, is dependent upon human practices'* (Jacobs et al 2005), and is constructed through the perceptions, beliefs and ideas of the individual.

In relation to this study, Owen's (1992) view on social constructionism clearly articulates the approach I wish to take:

"The claim and viewpoint that the content of our consciousness, and the mode of relating we have to other, is taught by our culture and society, all the metaphysical quantities we take for granted are learned from others around us" (Owen, 1992, pg 386).

The discussion that will follow includes a concise overview of the assumptions underlying the social constructionist perspective. The theoretical perspectives that are linked to the above three epistemology perspectives will now be described, as well as providing the rationale behind adopting a hermeneutic phenomenological approach.

Theoretical stance following a Social Constructionist view

Taking a social constructionist epistemological stance narrows down the possible theoretical perspectives that can be applied to this study. According to Crotty (2003) a theoretical perspective is a way of viewing reality, it becomes the 'lens' through which we observe, organise and interpret what we see. Therefore, we would need to consider a theoretical perspective which will lead us to identify aspects of Muslim women's lives, and aspects that are of interest, suggesting interpretations and understanding why some Muslim women seek health care for urinary incontinence and why others refuse health care.

Interpretivist approach

A theoretical perspective linked to constructionism is interpretivism. This perspective has its various branches and is used as an umbrella term that consists of other theoretical perspectives, ethnography, phenomenology and hermeneutics to name a few. These branches of interpretivism are all closely connected to the meanings that are associated with a set of actions or events by the participants under study (Gerring 2003).

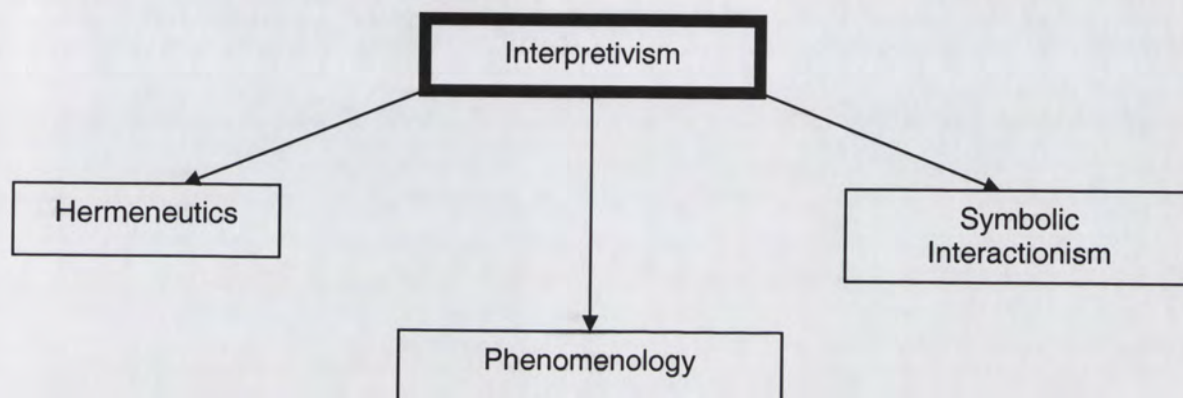


Figure 3 Branches of Interpretivism developed through my understanding.

Within the interpretivist approach it is impossible to separate facts from values, because knowledge is seen as something that is socially constructed, and not as discovered as an independent existing reality. Interpretivists are interested in culturally derived and historically situated interpretations of the social world (Crotty, 2003). Taking an interpretivist approach means searching for meanings that individuals construct, by looking at the context of an action or event, its connection to a surrounding set of actions, events, and interpretations (Gerring 2003). The goal is an in-depth exploration of a given phenomenon.

I will discuss briefly the approaches within an interpretivist paradigm and provide justification for using a hermeneutic approach in this study.

Ethnography

Ethnography as a methodology refers to the researcher actively taking part in people's (subjects) daily life over an extended period of time, watching, listening and asking questions (Hammersley and Atkinson 1995, Crotty 2003). This approach attracts the theoretical perspective of symbolic interactionism and focuses on

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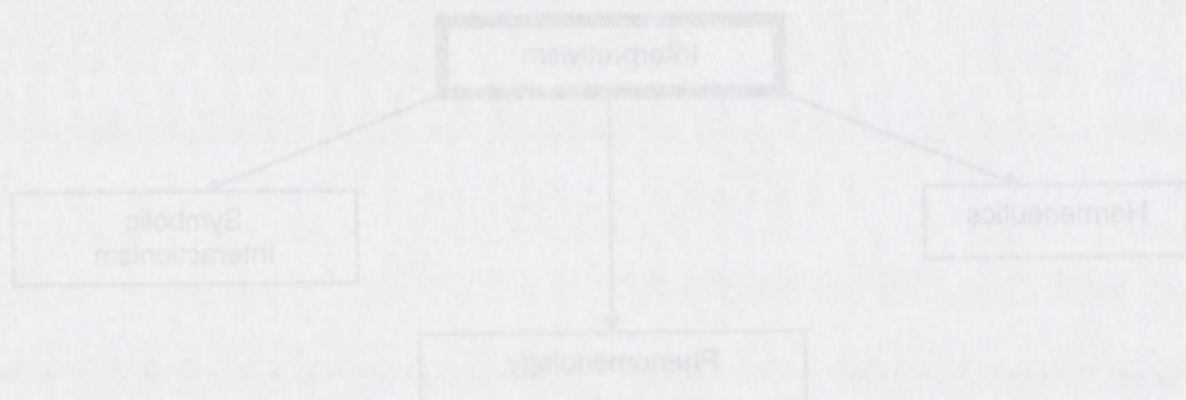


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people's practices and lived realities (Blumer 1986; Gray 2004). This perspective began with Max Weber (1864-1920) and George H. Mead (1863-1931), both of whom focus on the interaction between the phenomenon and the individual.

'Action' is the key term which describes symbolic interactionism, where the researcher becomes an observer and a part of the phenomenon. It has been argued that to understand the meaning of actions, the symbolic interactionist or ethnographer would require close contact and immersion in the everyday life of their participants (Caughey 1982). Meanings are therefore not fixed or stable but are revised based on experience (Crotty, 2003). In order to understand this process, a researcher would have to study the subject's actions, objects and society from the perspective of the subject themselves. In practice, this would mean the researcher entering the field and observing what is happening.

This approach would not have been suitable for my study. For example, ethnography as an approach requires a continuation of fieldwork that explores experiences as they are happening (Hammersley 1992). According to Hammersley and Atkinson (1995), the ongoing nature of fieldwork connects important personal experiences with an area of knowledge as it describes a particular culture. Social situations are seen as places where human beings recurrently interact in particular ways, and where people hold certain kinds of knowledge, ways of doing things, and perceptions that belong to those places (Corbetta, 2003). Therefore, the ethnographer's quest is to want to understand what one has to know, as a member of a particular group, to behave competently as a member of that group (Crotty, 2003). Therefore, the lived-through or existential qualities of personal experiences are sacrificed for the cultural or social focus.

Due to the nature of the ethnography approach and the nature of the study aims, this approach is inadequate, as such experiences cannot be observed.

My aim is to explore beliefs and practices, which cannot be observed. Participant observation would also not be possible or practical due to the subjective, personal, sensitive nature of the study topic.

Phenomenology

Phenomenology is another approach that is guided by the interpretivist perspective. Phenomenology is descriptive and pre-suppositionless. The researcher adopts a

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reflective attitude towards their own experience of the world by putting aside assumptions about the world's existence and character (Smith 2003, pg 53). Secondly, the researcher seeks to describe particular, concrete phenomenon (Hammond et al 1992). Phenomena are not the contents of the mind; they all involve an experiencing subject and an experienced object. As stated by Merleau-Ponty (1964) phenomenological description aims to make clear essential features implicit in the 'lived-world', the world as we act in it prior to any speculation about it.

Edmund Husserl (1859-1938) introduced phenomenology. In his opus magnum of *Logical Investigation* he suggested the need for a wide-ranging theory of knowledge and describes phenomenology as 'the experiences of thinking and knowing' (Moran 2000). For Husserl phenomenology was a transcendental science of pure consciousness or 'conscious recognition' which would involve human perceptions of reality.

Husserl's idea of conscious recognition is possible through what he terms as 'bracketing' or removing one's own preconceived ideas (Fitzgerald, 1995) of the natural attitude (Moran and Mooney, 2002).

Phenomenology for Husserl became the study of phenomenon, the way things appear to us in experience or consciousness. True 'knowledge of essence would only be possible by 'bracketing' all assumptions about the existence of an external world' (Moran, 2000).

Martin Heidegger (1889-1976) was a student of Husserl. He drew on the work of Husserl but disputed the idea of pure consciousness, intentionality and phenomenological reduction (Rockmore 2006). Husserl described bracketing as the key to his work and understanding of phenomenology, whereby phenomenological reduction becomes a process of defining the pure essence of a phenomenon (Dowling 2005). Heidegger opposes this belief and proposes that consciousness is not separate from the world of human existence. Heidegger argued that interpreting and understanding are essential and not just describing human experience (Polit and Beck 2004, pg 220). According to Cohen and Omery (1994) a central feature to Heidegger's phenomenology was to look past the everyday, normal meanings of life to see the larger meaning. Heidegger viewed the world as inseparable from the self. Observations, thoughts, feelings and experiences were so intertwined that separating them would be difficult. Heidegger argued that bracketing could not be achieved if the 'self' is actively involved in the world (Cohen et al 2000).

Phenomenology therefore became divided into two schools of thought: descriptive phenomenology (Husserl) and hermeneutic (interpretive) phenomenology (Heidegger), both offering ways of understanding a given phenomenon. A clear distinction between the two schools of thoughts is that Husserl's understanding of phenomenology was epistemologically based (theory of knowledge), whereas Heidegger rejects this view and understands phenomenology as ontology that is concerned with the meaning of 'Being' (Cohen and Omery, 1994).

Based on the above two schools of thought it can therefore be assumed that Husserl's descriptive phenomenology is aimed at identifying the structure of experience described by the participants, whereas Heidegger's thought allows further exploration by analysing the participants' descriptions of their lived experiences, as what they 'really' mean. The central difference between Husserlian and Heideggerian phenomenology centres on their different interpretations of the concept 'world' (Sukale, 1976). This study is based on South Asian Muslim women's narratives, which became the text for my interpretation and understanding. The aim of this study was to determine what an experience 'really' means for the individual. I believe it is impossible to bracket preconceived ideas, as I am actively involved in the world, also I believe as a Muslim woman myself, it would be impossible for me to 'bracket' off my own beliefs about the sample I wish to study as I myself belong to such as group. Therefore a hermeneutic phenomenological approach was adopted for this study, rather than the descriptive account described by Husserl.

The following section will consider hermeneutics as a method for research and will describe in more depth Martin Heidegger's as well as Han-Georg Gadamer's perspective of hermeneutics.

Hermeneutics as a method for social science

In this section I intend to explore in more detail what the term 'hermeneutic phenomenology' means, and how this may impact on the research question.

Historical origins

'Phenomenological philosophy is central to hermeneutic phenomenology as an approach for social science' (Cohen et al 2000, pg 6). Hermeneutics was originally a method used for interpreting sacred and legal texts (Martin and McIntyre 1994).

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Historically, religious leaders began identifying the literal or authentic meaning of religious texts so they could explain how to live a Christian life (Bryne 2001). An interpretation of religious texts was the historical hermeneutic thought. However mainly through the work of Heidegger and Gadamer, the methods of hermeneutics extended to cover the interpretation of all kinds of texts (Follesdal 1994).

Martin Heidegger (1889-1976): the notion of understanding for Heidegger was not aimed at re-experiencing another's experience but rather the power to grasp one's own possibilities for being in the world (Cohen et al 2000). Heidegger is well known for his published work titled '*Being and Time*', which at its most basic explores the question of '*what it means to be*', *What is being?*' Heidegger's main quest was to investigate *Dasein*¹⁷ or 'being there' (Crotty 2003), which emphasises the ontology of being.

Heidegger used the term *Dasein* to refer to human capacity to understand existence (Cohen et al 2000, pg 5), which is divided into three distinct areas:

- a) the attempt to understand the phenomena of the world as they are presented to us
- b) the attempt to understand how it is we go about understanding the world as it is presented to us, and
- c) the attempt to understand being itself

In Heidegger's view we live in an interpreted world and are ourselves hermeneutic; we are interpreters and understanders (Smith 2003). He believed that consciousness is not separate from the world but is a formation of historically lived experiences and 'culture' (Lawn 2006). What Heidegger believes is that our historical representation, the cultural traditions handed down through generations, shapes the way we view ourselves, our surroundings, others and the world in which we live. This pre-understanding was the root of Heidegger's theory of being in the world. He believed that culture or pre-understandings are part of us even before we become aware of them (Critchley 2001). Our experiences and meanings of the world are constructed, and such constructions will always be in reference to our cultural historical background. However, Heidegger is not interested in culturally derived meanings, rather in the phenomenology of human being or *dasein* (Crotty 2003).

¹⁷ *Dasein* German word for existence, 'being here' or 'being there'

Using this perspective of Heidegger and rejecting the view of 'bracketing' one's preconceptions is to embrace the idea that our preconceptions become part of the interpretations and meanings. To acknowledge these is to acknowledge that 'I' is actively involved in the world and we thereby become more concerned with uncovering such meanings rather than describing experience. For Heidegger we cannot distance ourselves from observation, feelings and thoughts, as we are a part of them. This approach is very important in relation to this study. For example, the religious and cultural background of these women is similar to my upbringing. This will influence the data generated, from both my own perspective and those of the participants in this study. To overcome my influence on the interpretations generated I have made clear my assumptions and their influence on the findings (Smith 2003) through a process known as reflexivity. In addition, we also accept that there may be many possible perspectives on a phenomenon. Cohen and Daniels (2001) state that when we turn a prism in one direction we see one side, and the other side becomes hidden and another open, therefore the data generated will be different when another researcher conducts the same research, in the same manner.

Laverty (2003) states pre-understanding is important for Heidegger, as he believed that this is not something a person can step out of, but something that is already with us. For Heidegger understanding without reference to our own background is impossible, the concept of understanding that Heidegger refers to is the 'understanding of existence'. This refers to understanding ourselves, through concepts concentrating on historical, cultural, and social levels (Laverty 2003), which are expressed as a linguistic articulation of understanding (Belzen 1997).

Understanding and interpretation is achieved through a hermeneutic circle, or 'the circle of understanding' (Crotty 2003). This moves from the parts of experience, to the whole experience, back and forth until our engagement with the data and text become rich in-depth interpretations of the phenomenon (Critchley 2001; Smith 2003).

The hermeneutic circle, or as Heidegger describes it 'the circle of understanding', is located in circular movements of interpretation in order to avoid possible loss of meanings (Moran 2000, pg 276). For such a process to occur we must not make analysis from outside the circle as this would develop an objective perspective of the data. Rather it consists of an inter-subjective form of participating in the structures of being that enables understanding. This is only possible through repeated movement

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among dialect to the whole and part which would change the meaning and add fullness to the understanding of the phenomenon (Moran 2000).

Hans-Georg Gadamer (1900-2002) was a student of Heidegger, who extended his work into a much more practical application. Gadamer supported Heidegger's ideas that all knowing and experiences of the world involve understanding and interpretation. In analysis of Heidegger's work Gadamer made the argument that the second of these definitions (as stated above pg 98) is an appropriate concern of human science. For Gadamer, hermeneutic phenomenology is exploring how people understand the world in which they live. His interest is not in the structure of phenomena, but in how the phenomena are interpreted. Interpretation is therefore the object of research (pg 254-264). Schleiermacher and Dilthey understood that hermeneutics related to uncovering the meaning of texts and historical events as a matter of understanding how the authors and actors of these texts and events understood them (Critchley 2001). However, Gadamer claims that as humans we are so conditioned by our position in history that it is not at all possible to return to the perspective of past authors and experiences (Lawn 2006). To understand the meaning of a text or event is, in Gadamer's view, related to one's concepts, pre-conceptions and prejudices.

Gadamer's hermeneutic emphasises the embeddedness of language in our understanding of the world (Gadamer 2004). He believed that understanding comes from interpretations embedded in our linguistic and cultural traditions, which contributes to our inherent prejudices (Gadamer 2004). Prejudices are preconceived notions of things arising from our experiences and socialisation. Gadamer states that it is absurd to think that it is possible to grasp the meaning of a text or event without judging its truth or rationality (Lawn, 2006). For Gadamer, to understand each other we cannot discard our experiences, and these experiences actually enhance our understanding. From the hermeneutic perspective, personal experiences are not a hindrance to the ability to understand instead they provide a contextual meaning. His interest is not in the structure of phenomena but in how the phenomenon is interpreted. Interpretation according to Gadamer should then be the object of research (Gadamer 2004), which becomes achievable only through language.

Gadamer's understanding of language and of understandings as being inseparable are similar to the views of Heidegger. Understanding such concepts involves the '*fusion of horizons*' (Gadamer, 2004). The perspectives of the author [subject] and

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Gadamer's understanding of language and of understandings as being inseparable are similar to the views of Heidegger. Understanding such concepts involve the 'fusion of horizons' (Gadamer, 2004). The perspectives of the author (subject) and

the interpreter [researcher] fuse to produce a new perspective. Gadamer adds that in interpreting a text we cannot separate ourselves from the meaning of a text. Understanding is an application of our prejudices and an interpretation is always possible due to our pre-understandings. Gadamer relates this application of understanding by a term known as '*phronēsis*'. Phronesis is a form of reasoning and knowledge that involves a distinctive mediation between the universal and the particular (Bernstein 1983).

The close link between hermeneutics and phenomenology is one that requires attention; philosophical beliefs differ among phenomenology and hermeneutics as stated above. From the above discussion it can be seen that hermeneutic phenomenology has been developed through the concepts and traditions of phenomenology, both deal with interpreting, understanding and experiencing a given phenomenon, but their approach is very distinct. The first difference between phenomenology and hermeneutics phenomenology relates to how the data is interpreted and the method of obtaining data. Phenomenology focuses mainly on the researcher's self-reflection on experiences of the phenomenon under study, which needs to be acknowledged and 'bracketed' and later addressed (Moran 2000), and on the participants' descriptions of their experiences.

Hermeneutic phenomenology tends to focus more on accounts of the 'lived experiences' through the interpretation, where our cultural and social aspects will inevitably influence this process, which then become a part of being (Cohen et al 2000).

Hermeneutic phenomenology is more concerned with understanding texts, and concentrates on historical meanings of experience and their effect on the individual and social levels (Lavery 2003). In this approach, the researcher aims to create a rich and deep account of a phenomenon through intuition, focusing on uncovering meanings and using prior knowledge as part of the interpretation process (Smith 2003).

My theoretical stance: Heidegger or Gadamer?

In this study I use a hermeneutic approach as outlined by Gadamer to meaningful material including texts; I will concentrate more on his approach than Heidegger's as it appears much easier to understand (Cohen et al 2000), also Heidegger is most

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interested in Being, whereas Gadamer's interest is in how the phenomena are interpreted (pg 5). By meaningful material, I consider such 'things' that express or are linked to the individual's beliefs, values and practices. An account of the interrelation between such actions, beliefs and values, will be considered in the findings chapters.

Hermeneutics is the art of interpretation. I believe concentrating on the four concepts developed by Gadamer may be helpful to understand why I chose Gadamer's hermeneutic approach rather than Heidegger's. Gadamer's four concepts are '*prejudices*', '*fusion of horizons*', '*the hermeneutic circle*' and '*play*'.

The theory of hermeneutics assumes that making meaning is a process that is embedded in the dialogue between the interpreter and the narrator, which becomes a back and forth movement between the wholes of texts and parts of texts in search of understanding (refer to pg 108). This process is referred to as the '*hermeneutic circle*', which represents the art of understanding (Annells 1996).

Gadamer stresses the importance of our historical consciousness within hermeneutics, which include the traditions and background that impact on our way of understanding (Gadamer 2004). Therefore, for Gadamer, understanding occurs from interpretations that are embedded in our linguistic and cultural traditions (Annells 1996) and that are also influenced by our *prejudices* or prejudgements developed through our past and present experiences (refer to page 109-110).

The *fusion of horizons* is a term that is related with Gadamer's thought. The term is usually understood to mean the fusion of the standpoint of two different people, such as the author and the interpreter (Annells 1996). Understanding takes place when these two horizons fuse together and it extends our vision. Gadamer explains the fusion of horizons as:

'more like a posture, a style, a way of living, or a way of conducting oneself than it is a way of knowing ... which results in greater self-understanding, a greater moral awareness, and an appreciation of other points' (Moody, 1990; pg 246).

His fourth concept of *play* is one that avoids the subject/object distinction. As seen previously in the above discussion, Heidegger and Gadamer oppose the objectivity that Husserl describes as bracketing. Gadamer does not contend with a subjectivist or objectivist position rather he describes himself as a player. The concept of play is central to Gadamer's *Truth and Method* (Lawn 2006). With the introduction of play Gadamer insists that play leads us towards understanding, what it means to be, towards the subject's attitudes towards some object (Reifel 2001). The to and fro

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movements of play are common in the hermeneutic circle in order to expand our horizon of understanding. This to and fro movement that Gadamer describes is the most significant. The reading of a text and understanding the narrator is hermeneutics, the art of interpretation and understanding.

Gadamer describes this as *'the player who sees the game as an object does not really participate in it and does not take it seriously ... being a player is not subjective because it is the game that is played and not the subject who plays the game'* (Gadamer 2004, pg 102-103).

An example of this in relation to the study in question would be that I as the researcher, or in Gadamer's terms a player, would enter the field of research (the participants and their narratives) with neither a subjective or objective view, rather a socially constructed view. The to and fro movements would consist of the process between my interpretations and prejudices against the meanings as they emerge from the texts, which would be used to broaden the horizon of understanding and eventually fuse into a new horizon (Walsh, 1996).

In an attempt to understand how South Asian Muslim women make decisions relating to their health and the services they access, it was necessary to consider the feelings, thoughts, beliefs, values and behaviours that individuals ascribe to the context of their world. Therefore, the study becomes guided by a hermeneutic approach, which is guided by the perceptions and beliefs of the individuals and understood through social and cultural perspectives (Crotty, 2003). This reality consists of meanings and interpretations that individuals give to their actions, other people's actions, social situations and objects (Mason, 2002).

Conclusion

This chapter has outlined the epistemological and theoretical perspectives of this study. I have provided a description of the approaches that have guided the study with consideration and justification for taking a particular approach. Taking a social constructionist approach allows the belief that that there is no such thing as objective truth but that knowledge is discovered through human practices. The aim of this study is to explore the meaning as constructed by the participants and their

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interactions with their world. This is the main aim of a hermeneutic approach: to explain, interpret and illustrate.

Heidegger's and Gadamer's illustrations of hermeneutics have been considered in this chapter as these two are the main advocates of this approach.

In the following chapter I go on to describe the research methodology used, based on the theoretical approach. This chapter will describe the participants, the recruitment process, data collection methods and ethical issues.

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Chapter 4

Methodology: the study of methods

The previous chapter concentrated on the epistemological and theoretical origins of the study. In this chapter, I intend to draw upon the methodology and methods employed within a hermeneutic phenomenological oriented study.

Introduction

This chapter explores the value of hermeneutic phenomenology as a methodology to guide the study. A methodology is a plan of action, a system of principles, practices, and procedures applied to a specific branch of knowledge (Crotty, 2003).

Following the hermeneutic approach adopted in this study the suggested methods for data collection will be considered. As this is an interpretive study to try and understand phenomena through meanings that participants in this study applied, I have adopted an in-depth interviewing method of data collection.

Firstly, I discuss the original design of the study. Following on from this I discuss the sample, the recruitment process, networking, preparations for the study, advertising, participant meetings, communication issues, piloting the interviews, and reflexive notes.

Ethical considerations that had to be taken into account throughout this study are outlined in the following section. I also endeavour to illustrate how I ensured quality in interpretive hermeneutic design, such as trustworthiness (Whitehead 2004), systematic data analysis process (Crist and Tanner 2003) and transparency (Turner 2003). These issues of rigour are covered within the data analysis section towards the end of this chapter, within which the initial analysis strategy is described followed by justification for the main analysis approach.

The methodological approach

Research devised to understand the nature of the phenomenon of religion as a 'referential frame' for Muslim women lends itself to the hermeneutics approach. The use of hermeneutic phenomenology enables the exploration of participants' experiences and further abstraction and interpretation by me based on personal

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knowledge. Hermeneutics adds the interpretive element to explicate meanings and assumptions in the participants' texts that participants themselves may have difficulty in articulating, for example, tacit practice knowledge (Crotty, 2003). Communication and language are intertwined and hermeneutics offers a way of understanding such human experiences, captured through language and in context (van Manen, 1997).

Methods

Before addressing the analysis stage I will consider the data collection method and methods that had been employed to access participants, sampling, recruitment, and advertising the study. This section will also discuss how the aims of this study were developed and refined.

What was planned?

For this interpretive study I decided to conduct interviews to gain an in-depth exploration of the given phenomenon. A hermeneutic study design is applied when there is little known about the subject area, or where new insights are required (Cohen et al 2000, pg 3).

Originally, through the aims of the study, I had decided to gain views on this subject area from a range of sources. The study was divided into two distinct phases, phase I and phase II. Phase I aimed at gathering perceptions and experiences of UI in relation to culture and religion, taking an exploratory approach, which is designed to 'discover' the underlying factors of a given phenomenon. In this phase, I interviewed South Asian Muslim women who had not sought help for symptoms of UI, using an in-depth interviewing technique. Alongside the interviews, initial translation of the two quality of life questionnaires, the ICIQ-SF and ICIQ-LUTSqol, was undertaken from English into Urdu. The translation followed a strict protocol produced by the ICS (International Continence Society) in the following manner:

1. Initial translation of the questionnaire – preferably undertaken by a bilingual native speaker of the language in question.
2. Back translation into English – preferably by a bilingual native English speaker, who was not involved in the translation stage
3. Review of translations and adjustment
4. Pre-testing for equivalence using bilinguals or monolinguals (ICIQ, 2006).

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The justification for translating these questionnaires was the fact that many older South Asian communities are unable to read or write in English, however they are used in clinical settings but have not been checked for cultural appropriateness in this group.

In phase II, a comparative approach was taken using semi-structured interviews. The focus of phase II was to compare two groups of South Asian Muslim women, who have and have not received health care services for UI. Additionally in this phase the face validity testing of the two translated questionnaires was completed, alongside a focus group discussion with a MDT urology team who provide and are in direct contact with people who suffer from urinary incontinence.

Prior to interviewing, I began with reviewing the literature on urinary incontinence and found very little work published on Muslim women (refer to chapter 2 literature review I). Therefore, I reviewed the wider literature on help seeking processes and the Muslim communities. In the initial stages of the study, I felt it was important to explain relationships between concepts of religion, culture and help seeking processes. At this stage, this led me to the grounded theory approach, which provides understandings of people's actions and beliefs about a common problem or concern (Schreiber and Stern 2001, pg 191), and which is used to generate substantive theory.

What actually happened?

Through carrying out the data analysis stages following the 'framework' approach developed by Ritchie and Lewis (2003) (refer to pg 121-123), I became aware that the impact of leaking urine for the South Asian Muslim women in the study was a complex phenomenon. Identifying and describing the process of health seeking behaviour was not sufficient enough as participants were discussing and disclosing the 'meaning' of leaking urine which was more important to them. Hermeneutic phenomenology is an approach used to discover meaning and achieve understanding of everyday lived experiences (Schreiber and Stern 2001, pg 191) of leaking urine that impact on South Asian Muslim women became clear. This influenced me to return to my data/findings and restart the analysis process using a hermeneutic approach as described by Cohen et al (2000) (refer to pg 123-128).

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Only through carrying out a grounded theory and a hermeneutic phenomenology stages of analysis did I realise that a true-grounded theory approach was not appropriate. Within a grounded theory approach there are strict guidelines the researcher must follow. The first of these refers to 'theoretical sensitivity'. According to Schreiber and Stern (2001), *'theoretical sensitivity is the ability of the researcher to think inductively and move from the particular (data) to the general or abstract...to build theory from observations of specifics'* (pg 60). In other words, prior assumptions or theories that the researcher has are recorded (memoed) and used in order to understand the processes being researched (Baker et al 1992), but do not influence the data, this is achieved through a technique known as constant comparison. This is the opposite in a hermeneutic approach, the researcher's prior assumptions and prejudices (what they think, feel and know) all become part of the narratives, findings and the interpretations. These interpretations arise through what Gadamer terms as the 'fusion of horizons', a dialectical process between the expectation of the researcher, the participants, and the meaning of the text (Gadamer, 1998). In Gadamer's view all prior assumptions and prejudices are condition to knowledge that determines what is intelligible in any situation (Lavery et al 2003).

Theoretical sampling is another key concept within grounded theory. This relates to gaining data from a number of sources to provide a wider perspective on the phenomenon (Wilson and Hutchinson, 1991). Additional sources of data were gained from a focus group discussion with health care professionals, followed by translating two questionnaires from English into Urdu. However due to the vast amount of data that I had accumulated, I decided to present the narratives of the 41 South Asian Muslim women and the 'meaning' that they had ascribed to leaking urine', which was the eventual aim of this study. The findings of the additional section, i.e. questionnaires or the focus group discussion are therefore not presented in this thesis, but will be reported in future publications.

Data collection method

Methods need to be consistent with the aims of a hermeneutic phenomenological study and investigate what the study sets out to investigate (Kvale, 1996). The scientific worth of qualitative methods also derives from the ability to communicate to others the systematic approach to the study of a phenomenon (Sandelowski,

1995). Qualitative interviews were chosen as the principal method of data generation. This method was chosen due to its flexible and exploratory nature, and because it allows for the in-depth study of participants' views on the subject matter. The topic itself, the impact of urinary incontinence in Muslim women (Chaliha and Stanton 1999), has received little attention. A method was required that would allow the exploration of South Asian Muslim women's accounts of their life world experiences of urinary incontinence that could be converted to text to allow interpretation, i.e. a group of people who have first hand experience of the phenomenon (Van Manen, 1990).

Therefore using in-depth interviews allowed me to explore aspects of Muslim women's lives that had not been considered in previous research. The aim was to bring to light, through exploration within a hermeneutic phenomenological framework, the experience of urinary incontinence and the impact of religious and cultural influences on help seeking behaviour.

This allowed the participants the opportunity to voice concerns or beliefs that they linked to seeking health care for urinary incontinence, as well as allowing me to probe further on interesting areas that emerged. The second reason derives from the nature of the key study question, exploring the lived experiences of those with UI. Hermeneutic phenomenology concentrates on the meaning that an individual assigns to a given phenomenon, through narratives or stories. It offers accounts of experienced space, time, body, and human relations as they are lived (Zurava, 2006). Applying the technique of interviews to social science research allows for alternative conceptions of social knowledge, of meaning, reality and truth.

One way of describing qualitative interviews is the notion of 'conversation with a purpose' (Mason 2002, p.67). The participants and the researcher form in a dialogue of their conceptions of the lived world. This allowed participants to share personal information and opinions, to talk freely about their experiences, which they believe were relevant, and reflect these experiences through a conversation, using language they [participants] know best. It also allowed me to ensure that rich data was generated through the use of prompting and probing questions.

Nature of sample sought

The focus of the study was on South Asian Muslim women. The term South Asian has been used here to refer to those women who originate from the South Asian sub-continent or those who identify their ethnic origin as such (which included Indian,

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Therefore using in-depth interviews allowed me to explore aspects of Muslim women's lives that had not been considered in previous research. The aim was to bring to light, through exploration within a hermeneutic phenomenological framework, the experience of urinary incontinence and the impact of religious and cultural influences on help seeking behaviour.

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One way of describing qualitative interviews is the notion of 'conversation with a purpose' (Mason 2002, p.87). The participants and the researcher form a dialogue of their conceptions of the lived world. This allowed participants to share personal information and opinions, to talk freely about their experiences, which they believe were relevant and reflect these experiences through a conversation, using language they (participants) know best. It also allowed me to ensure that rich data was generated through the use of prompting and probing questions.

Nature of sample sought

The focus of the study was on South Asian Muslim women. The term South Asian has been used here to refer to those women who originate from the South Asian sub-continent or those who identify their ethnic origin as such (which included Indian,

Pakistani, and Bangladeshi people) who are Muslims, and lived within the Northwest of England.

Recruitment

Through initial meetings with the supervisory team, it was established that research in the field of continence was lacking within racial groups such as Muslim communities (Wilkinson and Williamson 1995, Chaliha and Stanton 1999, Wilkinson, 2001). Another important aspect was related to the lack of utilisation of the continence services by the South Asian Muslim women in the Northwest of England (evidence gained from patient list discussed in the Introduction chapter pages 5-6).

The inclusion criteria for participants were: South Asian females, aged over 18 years, have symptoms of leaking urine, follow the Islamic religion, and living in the Northwest of England. The comparative element was to include within the sample participants who had or had not sought help for their UI symptoms.

There are a number of advantages to be derived from taking a comparative approach including the fact that differences found may serve to illuminate cultural identities of both groups. It is likely there will be a difference in cultural identity between those who do/do not access health care.

The sampling strategy

In consideration of the comparative aspect of the study, I chose to gather the sample through a strategy known as purposive sampling. Several authors have recommended this strategy where exploration is a key factor (Denzin and Lincoln 2000; Patton 2002). Parahoo (1997) states this type of sampling is used to select participants that 'fit the criteria' and who are likely to produce valuable data. This method is also consistent with a hermeneutic phenomenological approach as the aim is to look for culturally derived and historically situated interpretations of the social world (Crotty, 2003). In other words, those participants chosen for the study can illustrate the phenomenon of religion, and in particular Islam, as a referential framework. Gaining access: Making contacts and establishing links

Data collection began in April 2006. Prior to this I had spent nine months reviewing the literature on urinary incontinence and establishing links with organisers of

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community events targeted at the Asian communities, primary care trusts (PCTs), private organisers of health events.

Throughout this period, I worked closely with a consultant uro-gynaecologist (fund holder), nurse specialists, continence advisors and physiotherapists, to help me gain an in-depth understanding of the physiology and development of urinary incontinence. I gathered literature on the causes, treatment and management of UI, which has formed part of the background chapter to the study. Through this work, I was able to identify areas which had received little attention. I also presented these findings to the supervisory team, who supported my decision to engage in this area of study.

Deciding the area of study

Making contact with potential participants was put on hold until I determined which areas within the Northwest of England would need to be targeted to advertise the study. The demographic data of study area was consulted to work out the percentage of South Asian Muslim communities living in the Northwest area.

The data revealed that the largest minority ethnic groups in the Borough were those of Indian origin (10.7%) and Pakistani origin (8.7%) (www.bwdpct.gov). The areas where they lived were inner city, and included seven neighbourhoods. These suburbs subsequently became the targeted areas for advertising for participants and the study.

Informal and Formal meetings: The negotiation process

Informal meetings took place within the University of Central Lancashire with colleagues who had conducted research and were research students. The purpose of these informal meetings was to identify how others had recruited potential participants and advertised their work. It was identified very early that the colleagues I spoke to had not recruited Muslim women in their sample, nor was communication an issue.

Asian community centres and organisers in the above areas were contacted via telephone and letter, to arrange a formal meeting. The purpose of these meetings

community events throughout the study period. The study was approved by the research ethics committee of the University of Hong Kong.

Throughout the period of the study, a research assistant (a female, Chinese, and an in-depth understanding of the Chinese culture) was assigned to the study. In addition, I gathered information on the Chinese culture and the Chinese community from a book which was formed part of the study and was available to the research assistant. The research assistant was able to identify events which were relevant to the study and to provide information on the study to the supervisor. The research assistant was also able to provide information on the study to the supervisor.

Deciding the area of study

Making contact with potential participants was the first step in the study. The study was conducted in the area within the borders of the Hong Kong Special Administrative Region. The demographic data of the area was obtained from the Census of South Asian Muslim community in Hong Kong. The data revealed that the population of the area was 10,750 and that the population of Indian origin (10.7%) was 1,150. The area was a multi-ethnic area and the population was subsequently divided into the Indian, Chinese, and other ethnic groups. The study was conducted in the area.

Informal and Formal meetings: The research process

Informal meetings took place with the participants in their homes. The participants who had contact with the research assistant were invited to the study. The informal meetings were held at the homes of the participants and were held at a time convenient to the participants. The participants and the research assistant discussed the study and the participants' views on the study. The participants were also asked to provide information on the study and to provide information on the study.

Asian community centres and organisations in the Hong Kong were contacted by telephone and letter to arrange a formal meeting. The formal meeting was held at the

was to discuss the intent of the study, and identify how to access this community. Organisers of community centres identified many Asian women attending sessions on health and fitness, sewing, cooking, and English for Speakers of other languages (ESOL) sessions aimed at teaching women to speak read and write English. I did not attend all these sessions but decided to concentrate on one, which will be discussed further.

These meetings provided opportunities to obtain views about the initial concerns of Muslim women. An immediate response was not anticipated, as many viewed the subject of urinary incontinence '*as a very private matter something that should not be discussed with others*'. Although organisers seemed interested, concern in recruiting participants due to the nature of the subject was expressed.

Informal meetings with Muslim women in the communities were carried out. These informed me of the challenges that some Muslim women face in their daily lives, sometimes at the hands of their male relatives. The decision to talk to someone outside their family circle was raised and was an issue that they as children had been told not to do (these issues are discussed in more depth in chapter nine).

One organiser from a community event showed disgust about the subject area. The response was '*if we had this problem we would be in hospital.... It does not happen to us*'. At this stage, it became quite apparent that South Asian Muslim women would not be willing to talk to a *stranger* [myself] about urinary incontinence. I therefore decided to change the approach.

I decided that my professional background as a nurse would allow me access to Muslim women with UI. For potential participants, I then changed from a stranger, who wanted to know about such a private matter to a health care professional, who would understand the physiology of leaking urine. As a Muslim woman myself, I would understand their religious and cultural practices.

Preparations: advertising the study

Due to the comparative nature of the study, visual advertising for the study was presented in two different institutional settings: the community centres and hospitals in the study area (refer to appendix seven, advertisement in both Urdu and English format).

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Advertising the study amongst South Asian Muslim women who had not sought help

It has been found in previous research that people can communicate verbally in any language but understanding or reading for him or herself is not always possible (McFarland et al 1989; Bhopal 1991; Naish et al 1994). For this reason, advertisements for the study were presented both verbally and in written format. For the Muslim communities the common language is that of Urdu, generally, if reading Urdu was difficult the speaking was not. Therefore, the written information was provided in Urdu and English format.

Posters and flyers (appendix seven) were published in Urdu and in English and placed in the community centres identified. From the sessions identified, I decided to access potential participants through ESOL sessions. The reason for this was that people wishing to reside in the UK are required to provide evidence (certificate) of achievement at level three of English, verbal and written. This is confirmed in the document titled 'UK-Major Immigration Changes in 2006 and beyond', published in 2007. It states *'those wishing to gain permanent residence would from 2nd April 2007 be required to show knowledge of the English language and UK culture by passing a 'Life in the UK' test'* (Home Office 2007). Secondly, my ability to communicate in another Asian language was poor therefore I felt that targeting those who may have some understanding of English would be helpful. This is discussed further on pages 113-114 under communication issues.

A 5-10 minute talk about the project was given in English and Urdu. The verbal sessions then took place in a classroom setting, with the permission of the lecturers. Potential participants were all given information packs, which consisted of an invitation letter, information sheet, consenting forms, demographic data questionnaire and flyer about the study. All the information was given in both Urdu and English (refer to appendix six for full information pack, in Urdu and English).

Advertising the study amongst women who had sought help

Previous research has also identified that people who are unable to communicate directly with health care professionals are more than likely to be accompanied by friends or family members, to bridge the gap of communication (Bhopal 1991).

The professional contacts I had made informed their patients about an upcoming health-promoting event aimed at Muslim women with urinary incontinence. I was then invited to inform these patients about the study verbally and provide them with information packs. I also worked in clinics with consultants and nurse specialists, to

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gain access to Muslim women seeking health care, and inform these women about the study.

Posters and flyers were also placed in the general outpatients' department (GOPD) uro-gynaecology at the study site (refer to appendix seven for poster and flyers in Urdu and English).

The participants

The age range of 18 years and over was to allow exploration of practices and beliefs of younger and older South Asian Muslim women. Cultural practices are likely to change over time, for what one generation considers 'culturally acceptable' may not be similar to the next generation (Marwa 2000). The advantage of incorporating this range of experiences, practices and beliefs is the richness and depth of data obtained and the use of multiple perspectives to illuminate the phenomena under study.

Men were not included in this project. The reason for focusing on females was that this condition is not gender-neutral, and significantly more women suffer from this condition than males. I also believe that as I am a Muslim woman, questioning Muslim men would not have proved beneficial, as this is not 'culturally acceptable behaviour'.

This diversity in the characteristics of the sample allows richness to the data and is a valued aspect of interpretative paradigm research. Overall, 41 participants were included in this study. Fourteen participants had sought help and 27 had not sought help. For a full description of the demographic details, refer to appendix five. Details presented include the age, marital status, and medical history, number of children, country of birth, number of people per household, profession, identity and the length of the interview.

Individual meetings

Once the information packs were distributed to potential participants, I informed these participants that they had 48 hours to contemplate their decision to participate in the study. I also informed them that if they required any more information then my contact number was provided on the information sheets.

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The age range of 18 years and over was to allow exploration of practices and beliefs of younger and older South Asian Muslim women. Cultural practices are likely to change over time, for what one generation considers 'culturally acceptable' may not be similar to the next generation (Ahmed 2000). The advantage of incorporating this range of experiences, practices and beliefs is the richness and depth of data obtained and the use of multiple perspectives to illuminate the phenomena under study.

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All participants that decided to participate were met face to face in their own homes, a week prior to the interviews, and verbal and written information about the study was provided. Many of the participants requested more information about the study, which usually included details from the information provided, which had not been fully understood by them due to the low literacy skills. Confidentiality and privacy was a major concern of the participants. I reassured participants as much as possible and informed them that my role was to maintain a high standard of professionalism. Individual meetings then took place in the participants' chosen environment.

Only when participants were fully aware of their role, the role of the researcher and the intent of the study, were dates arranged for the interview time and place to suit each participant.

Communication issues

After the individual meetings, I became increasingly aware of my inability to communicate effectively in Urdu, and their [participants] inability to communicate effectively in English.

Participants informed me that their preferred language of communication would be Punjabi or Urdu for the Pakistani and Urdu or Gujarati for the Indian participants. The common language then became Urdu, and to provide effective communication between the participants and myself I decided to increase my basic knowledge of Urdu. I enrolled on a 12-week Introduction course to increase my ability to communicate in Urdu. Understanding the Urdu language for me was not a problem but counter-responding in appropriate Urdu words was.

Out of the 41 participants interviewed, 26 interviews were conducted in Urdu/Punjabi and 15 in English. In order to carry out the individual interviews in Urdu I hired a private translator to provide a channel of communication. The translator was informed about the study in detail, and was aware of the issues which I intended to cover. I contacted the translator only when I needed their assistance, and only when participants agreed for a translator to be present. Amongst the 26 interviews conducted in Urdu only five interviews were conducted with the translator present.

For the older participants the main language was Urdu/Punjabi, with occasional words of English. For the younger generation, switching between Urdu and English was common. Participants born in the UK refused to have the translator present as they felt intimidated with the amount of people present. Some older women also

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refused, and felt their daughters or daughters-in-law would provide translation where necessary.

Topic guides for interviews

Two different topic guides were developed throughout the project. These guides were based on key findings from the literature review, and my personal beliefs about the decisions that Muslim women take in order to engage in health care activities. The interview guide provided a means to maintain continuity and flow of the interviews and to provide direction if the participants began discussing issues not relevant to the project. Prompts were listed towards the end of the interview guide, to enable me to probe further for additional details/information if required (refer to appendix eight for interview guide).

Piloting the Interview Schedule

A group of four colleagues from the local hospital took part in the piloting of the initial interview guide. There were two reasons why I choose to pilot the interview schedule. The first was to identify areas within the interview schedule that may need to be amended and to ensure the questions were generating data relevant to the aims of the study. Secondly, it became a way for me to become familiar with the whole interview process, as this was my first experience as a researcher. However, interviewing or gaining information from patients about their health is common within my profession.

Verbal consent was sought prior to commencing the pilot interviews. All four participants were informed that the data received from them would not be used in the main study and would only be used for my benefit in refining the interview schedule and ability to interview.

The interviews were audio-taped and deleted once I had received feedback on the positive and negative aspects of the interview process and my interviewing technique. All four participants identified the interview schedule as too long, as the interviews in the pilot study lasted approximately 2 hours 30 minutes. Participants voiced concerns about repetition of questions on urinary incontinence, concerns were voiced about the speed of the interview, and some participants felt they were rushed. The schedule was changed appropriately and interview techniques related to the speed of posing questions and the use of prompts were revised (appendix eight).

Interview Guide

The guide for the first set of interviews (South Asian Muslim women who had not sought help) concentrated on general knowledge relating to UI, including causes and the affect of UI on their daily life. Aspects of religion and culture were also explored around the issues of UI, and what prompts them to seek help for medical purposes. This guide provided an initial mapping, which could be built on in the next set of interviews (South Asian Muslim women who had sought help). These interviews included similar topics, but also dealt with women's perceptions of continence care.

Additional Field notes

Hand written notes

Throughout the process of the interviews, I maintained a notebook, in which I would place the time of the interview and when it ended. The notebook also became a part of the analysis as I began to note issues such as the seating arrangement between the participant and myself, and sometimes with a third person (daughter, daughter-in-law, or child). Common practices also became details of the reflexive diary, for example the removing of my own shoes as I entered the house, waiting to be seated, and the seating area for the participants. These issues are covered in-depth in the reflexivity chapter. Once the interview was completed I also wrote in this reflexive diary my thoughts about the interview (refer to appendix fourteen for extracts from some of the interviews).

Audio recording

All participants were aware that the interview would be recorded. Throughout the interviews I placed the audio recorder in such a place that it was visible to both the participants and me. The audio recorder was only turned off when the interview had ended or at the request of the participants. These requests were usually due to them disclosing personal information about themselves, such as their relationships or family matters.

Ethics and ethical considerations

Ethical approval and considerations are required in any research project carried out on 'living things'.

Ethical approval was sought and gained from four committees:

- a) Lancashire and South Cumbria Agency was gained on the 28th October 2006.

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- b) Research and Development (R&D) at the local hospital on 8th November 2006.
- c) Faculty Ethics Committee at University of Central Lancashire on the 13th November 2006, and
- d) Primary Care Trust (PCT) of the study area 23rd October 2007.

The study was funded by Pfizer Global Pharmaceuticals, and a Consultant uro-gynaecologist based at the study site.

Ethical considerations: respect of rights and dignity

Ethical considerations that arose from this project were related to obtaining consent and maintaining participant confidentiality. These issues will now be discussed.

Informed Consent

Obtaining informed consent is a pre-requisite to the involvement of research participants in any project. The notion of informed consent has been addressed widely in the literature (Smythe and Murray 2000; Mauthner et al 2002). People from the ethnic minority populations, such as Muslim women in this study have been classified under 'special considerations', mainly for reasons of language and communication.

Given that participants in this study may be likely to have issues regarding literacy in the own languages, I had to be aware of assumptions regarding the individuals' level of proficiency in either English or Urdu, without offending the participants. For this reason I verbally delivered all the information provided in the written documents (refer to appendix six for information packs) in Urdu and in English, to ensure that participants understood the information and to guard against any offence. Oral consent was obtained as well as written consent. This allowed the participants time to read the consent form, and later allowed me to question their understanding of what their role and my role entailed (for a copy of the consent forms refer to appendix six). Providing participants with a translation of the written consent form and information sheet was deemed a suitable strategy to ensure the participants had full access to the information provided, and could further discuss with significant others or myself if required.

- b) Research and Development (R&D) at the local hospital on 8th November 2006.
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Participants were all informed that their participation in this study was voluntary, and refusal to take part would not effect any medical treatment they may require in the future. Participants were also informed they were free to stop participating at any stage, and that this would not affect their status or rights.

Storage of data

Under the Data Protection Act 1998, it is the duty of the individual [researcher(s)] to ensure that data collected is stored securely. In order to comply with University of Central Lancashire ethical regulations, data was stored within the premises of the University itself.

All collected data (interview transcripts and CDs that held information about the participants) were placed in a secure filing cabinet at the University. Computerised records were password protected.

Confidentiality and Anonymity

Due to the sensitive nature of this subject, participants were informed that information disclosed regarding the subject area would remain between them and me. Participants were informed that findings would be disseminated at conferences, published in articles and finally in a thesis. Confidentiality and anonymity would be maintained through the use of pseudonyms, and no information that could identify them would be disclosed. Participants were also informed that the supervisory team would have access to the transcribed interviews; however, personal information, which could identify participants, would not be available on the transcripts.

Ensuring Quality: Credibility, dependability and conformability

It has been argued that the notion of positivistic references of reliability, validity and generalisability present inadequate assessment criteria to be applied to qualitative research studies (Maxwell 2002, Schofield 2002). A number of different criteria deemed more appropriate to qualitative enquires have been suggested by Lincoln and Guba (1985) including credibility (internal validity), dependability (reliability) conformability (neutrality) and transferability (external validity). These issues will now be considered in relation to this project.

Lincoln and Guba (1985) suggest that 'peer debriefing' is one strategy which can be employed to increase the credibility of qualitative research. This strategy allows others to critically review the implementation and evolution of the research methods employed. Lincoln and Guba (1985) state, 'peer debriefing is the process of exposing

Participants were all informed that their participation in the study was voluntary and that they could withdraw at any time without penalty. They were also informed that their participation would not affect their future. Participants were also informed that their participation would not affect their future. Participants were also informed that their participation would not affect their future.

Storage of data

Under the Data Protection Act 1998, it is the duty of the researcher to ensure that data collected is stored securely. In this study, the data was stored in a secure location. The data was stored in a secure location. The data was stored in a secure location.

All collected data (interview transcripts and field notes) were stored in a secure location. The data was stored in a secure location. The data was stored in a secure location.

Confidentiality and Anonymity

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Ensuring Quality: Credibility, dependability and transferability

It has been argued that the notion of bias is not a neutral one. It has been argued that the notion of bias is not a neutral one. It has been argued that the notion of bias is not a neutral one.

Lincoln and Guba (1985) suggest that there are four strategies that can be employed to increase the credibility of qualitative research. The strategies are: (1) prolonged engagement, (2) persistent observation, (3) triangulation, and (4) member checking.

oneself to a disinterested peer for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind' (pg 308).

In order to meet this criterion I have worked with colleagues from a number of different backgrounds to identify and explore my own perception and areas of concern in undertaking this research. This provided me not only with valuable incentives in terms of potential avenues to explore and areas to consider, but also contributed to reflection about my position within the wider context of this project. In addition to this, findings and developing interpretations were shared with colleagues and participants, to actively seek agreement or potential pit-falls. According to Flick (2006), providing this process increases the procedural dependability of qualitative research.

To ensure credibility, or internal validity, I collected data from participants in their preferred language, mainly Urdu/Punjabi or English. The interviews that were conducted in Urdu were translated into English and checked against the original Urdu version. The independent translator also helped with the checking of the original translations. I also invited participants to read the initial interpretations of the data, which has been referred to as 'member checking' (Lincoln and Guba 1985). However, none of the women interviewed took up this suggestion.

Dependability or reliability was maintained by keeping a diary of daily events throughout the whole research process. Throughout the interviews, I maintained a notebook which consisted of the time, date, the environment, and responses that subsequently formed part of the analysis process (refer to appendix thirteen). All interpretation of the data as well as stages of interpretations and themes as they emerged were all maintained, updated and saved on a word document. This helped to provide visible documentation as evidence of my analysis and interpretations of the data (refer to appendix 10, 11 and 12).

Conformability or neutrality, according to Denzin and Lincoln (2000), is used in the context of the constructivist paradigm to replace what is usually referred to in a positivist paradigm as objectivity. The underlying aim is in principle the same: 'to enable the audience to judge the findings of a given study which can be derived from the data generated' (Ritchie and Lewis 2003). This was carried out in the form of presenting findings at conferences and presentations of the findings to the multi-disciplinary urology team. My own perspectives and those of the participants were

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presented in such a manner that those within the groups were able to identify how I arrived at the data generated.

The above are basic guidelines for any qualitative study to ensure quality is maintained. Within the hermeneutic approach I take in this study, reference to a reflexive journal is important, as this is the hallmark of hermeneutic research (Koch 2008). Reflexivity requires us 'to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research' (Nightingale and Cromby 1999, pg. 228). Chapter 14, 'a personal account', is dedicated to my journey as a researcher, a Muslim woman and a nurse.

The following section will now consider the data analysis strategy. This section will be divided into two sections, the reason for this is that the initial analysis began with the 'framework' designed to analyse data in a grounded theory approach. Only through carrying out this process did I understand that the analysis did not correspond with the hermeneutic approach adopted in this study.

Strategy of analysis

The leading question developed during the initial stages of enquiry was that of, *'What are the views of South Asian Muslim women in relation to urinary incontinence and do their religious and cultural beliefs influence them when seeking health care for this need?'*

Initial Data analysis

I used Ritchie et al's (2003) 'Framework' model to guide the data analysis in order to obtain an accurate description of Muslim women's experiences and the meanings they assign to such events (Crotty, 2003). The 'Framework' approach is a flexible tool that can thematically analyse data.

This approach develops a hierarchical thematic framework that is used to classify and organise data according to key themes, concepts and emergent categories. The appeal of Ritchie et al's (2003) 'framework analysis' lies largely in its explication of steps that can be followed, including indexing, charting, and mapping. Five stages of analysis were identified and used from Ritchie et al (2003) framework, which will be briefly described further on page 121-123.

Interpretations and translation

As identified above the interviews were audio taped with the permission of the participants. The in-depth interviews generated 60 hours and 18 minutes of tape. The interviews conducted in Urdu were interpreted by myself and the translator, and were checked against the original to indicate true (refer to appendix one for terms) interpretation had taken place. Literal translation was not always possible, though a conscious effort was maintained to stay true to the original meanings. The taped interviews were copied onto CD format, and interviews transcribed on to a word document.

The process of transcribing the interviews from Urdu into English, and reading and re-reading the transcripts against the actual recordings, enabled me to become more familiar with the data. Through this process I was able to begin to identify similarities and differences among South Asian Muslim women who had not sought help compared to South Asian Muslim women who had sought help.

Transcription

Transcription involves close observation of the data through reading and listening to the recorded interviews (Bailey 2008). Each interview was read initially to become familiar with the data generated.

Initial analysis

Printed transcripts were then marked with coloured marker pens to identify initial themes. 'Embarrassment', 'fears of examination', 'religious obligations' were all themes that were recurrent. These themes together with others identified by participants were used to develop an index guide of the overall themes, with sub-themes and sometimes sub-sub-themes (refer to appendix 10, for themes identified).

A summary chart of the themes was maintained throughout the process of reading and re-reading the transcripts. Two summary charts were developed, which were revisited on an iterative and flexible basis as data analysis progressed. The next stage was to provide a theme/sub-theme/ sub-sub-theme chart with direct/illustrative quotes (see appendix 12, for extract from the chart). This chart contained enough information to prevent having to read the transcripts again, and contained the page numbers, number of participants were identified for easy access. This enabled me to identify what the overall theme and sub-themes were.

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There are a number of advantages to be derived from the production of a written transcript of an interview. Transcripts allow a visual aid in the analytical thinking process. In addition, transcribing data into written language supports the research process as it allows the data to be edited in such a way as to maintain anonymity.

Five stages of 'Framework' approach

1. Familiarisation

In order to interpret the data generated, I decided to listen to the recordings of the interviews, whilst reading along the transcribed printed interviews. I used coloured pens and post it notes to highlight areas which resonated throughout the interviews (refer to appendix 14 for a review of the initial coding).

2. Initial stage of developing themes and sub-themes

Ritchie et al (2003) defines this stage of analysis as the basis for identifying a thematic framework. This involves describing and identifying all the key issues, concepts, and themes by which the data can be examined and referenced. This was carried out by drawing on a priori issues and questions derived from the aims and sub-aims of the study as well as issues raised by the participants themselves and views or experiences that recurred in the data. The product of this stage was a detailed index of the data, which labelled the data into manageable portions for subsequent retrieval and exploration (see appendix 12 for detailed table of analysis).

3. Second stage of developing themes and sub themes

Ritchie et al (2003) refers to this stage as the *indexing and charting* phase, which involves constructing a manageable index for the data. This is achieved by providing links between each category, applying the thematic framework or index systematically to all the data in textual form by assigning the transcripts with themes or codes from the index, usually supported by short text descriptors to elaborate the index heading (appendix 12 for detailed table of analysis).

4. Thematic analysis or Mapping and interpretations

The aim of this stage is to generate an understanding of participants' perceptions, views and beliefs towards UI and the affect on the life of Muslim women. The two initial stages of analysis become the base for the third level, which then becomes the core category (a term used in grounded theory). During this stage, the central category of the affect of religious beliefs on help-seeking behaviour was identified.

This stage of the analysis consists of:

There are a number of advantages to this approach. First, it allows the researcher to have a clear and concise overview of the data. Second, it allows the researcher to have a clear and concise overview of the data. Third, it allows the researcher to have a clear and concise overview of the data. Fourth, it allows the researcher to have a clear and concise overview of the data. Fifth, it allows the researcher to have a clear and concise overview of the data.

1. Familiarisation

In order to interpret the data generated, the researcher must first become familiar with the data. This is done by reading through the data and identifying the main themes and concepts. This process is often referred to as 'familiarisation'.

2. Initial stage of developing themes and codes

Richie et al (2003) define this stage as 'the initial stage of developing themes and codes'. This is done by identifying the main themes and concepts in the data and developing a list of codes to represent these themes. This process is often referred to as 'initial stage of developing themes and codes'.

3. Second stage of developing themes and codes

Richie et al (2003) refer to this stage as 'the second stage of developing themes and codes'. This is done by refining the list of codes and developing a list of themes. This process is often referred to as 'second stage of developing themes and codes'.

4. Thematic analysis of coding and interpretation

The aim of this stage is to generate an understanding of the data. This is done by identifying the main themes and concepts in the data and developing a list of codes to represent these themes. This process is often referred to as 'thematic analysis of coding and interpretation'.

- Defining initial concepts
- Mapping range and nature of phenomena
- Creating typologies
- Finding associations
- Providing explanations

5. *Product and stories*

The final stage of analysis is described by Ritchie et al (2003) as *product and stories*. This refers to drawing conclusions from the data and from what the participants have disclosed, and referring this back to the original aims and objectives of the study.

It was at this stage of the analysis that I began to realise that my aims were covered but the participants had disclosed narrative issues that I had not intended to explore. These themes were a part of them, their experience and their lives. These themes were repeatedly emerging in relation to 'racism' and the recent 'terror attacks'.

The initial strategy used to analyse the data provided a systematic guide on how to analyse qualitative data (grounded theory approach), which is not in line with the hermeneutic approach. According to Crabtree and Miller (1999), this method for analysing data is too technical and non-hermeneutic, without regard to the researcher's assumptions and practices to adequately incorporate reflexivity (pg 149). This approach was too deconstructive, the process of breaking down into codes and meaning units, which is opposed in a hermeneutic approach. Hermeneutic inquiry explores resonant meanings, to understand life as it is lived, by those living it. The meanings represented the cultural upbringing of these South Asian Muslim women living in a Western world, which became paramount in understanding, interpreting and applying meanings by exploring the context in which it occurs, rather than a more 'objective' deconstruction manner. More importantly taking the 'framework' approach did not allow me to situate myself within the analysis process. According to Lyons and Coyle (2007) within the grounded theory approach the researcher's role is to discover and present the actor's meanings and understanding in a particular context. The distance placed between the data and the researcher in the analysis stage is one that is important and paramount. In a hermeneutic approach the researcher engages in an interpretative activity. The researcher's pre-existing knowledge and conceptions are therefore actively implicated in the analytic process as the researcher tries to describe and account of participants' experiences (Lyons and Coyle 2007).

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- Providing explanations
- Finding associations
- Creating typologies
- Mapping range and nature of phenomena
- Defining initial concepts

5. Product and stories

Taking an overall hermeneutic approach to the study allowed room for such data to become a part of their stories, described by Cohen as '*a journey that is neither controlled nor predicted*' (Cohen et al 2000, pg 3).

Four stages of analysis following a hermeneutic approach

The aim of hermeneutic phenomenological analysis of data is to ensure that patterns and relationships identified as central to the research are identified as part of the data generation process, rather than imposing preconceived themes on the data (Ritchie and Lewis 2003). Under the influence of Gadamer's hermeneutic approach, the analysis of texts involves not privileging what the author means, but using a more creative mode to develop new meanings (Lawn 2006). In other words, this is not the meaning that I assign into the text, nor is the meaning purely brought from the text. Meaning comes into being in and out of the reading, through the fusion of horizons. In Gadamer's words this process is known as 'the arts of interpretation', the process of reading and re-reading that will eventually contemplate a picture by the eye of the beholder (Gadamer, 2004), a picture, a story that was developed by the participants and presented through the process of interpretations.

I am involved in the world, I became active in the world of the 41 participants, and maybe my presence in their life at the stage of interviews contributed to the disclosure of the issues. Within this approach, reflexivity is necessary in shaping the process of interpretation and making explicit our own prejudices and preconceptions that affect the interpretation generated. The ability to identify my own prejudices throughout the research process proved to be beneficial as it allowed me to keep a written reflection of difficulties and achievements together which helped with the 'writing process' that guided and shaped the study (see appendix fourteen for extracts from field notes).

In keeping with the methodological approach adopted, the approaches to data analysis from phenomenology and hermeneutics were drawn on to inform the data analysis stages. Throughout the stages of analysis I drew back on the actual transcripts to familiarise myself with the data, and to provide as 'true' (refer to glossary of terms) an interpretation as possible. This strategy is known as 'authenticity' (Lincoln and Guba 2000), which in its basic form means staying true

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and fair to the data and the participants. The authentic nature was also maintained as the supervisory team all had copies of the transcripts to date. This increased the authenticity of the findings, as others were able to identify how the interpretations and findings were conveyed.

There are no methods assigned to the hermeneutic approach, as this approach strongly opposes methods (van Manen 1990, Cohen et al 2000). According to Gadamer understanding is a practical, situated activity. Hermeneutic analysis according to Benner (1994) focuses on texts as a research data source, which can be generated through stories, interviews, participants' observations, literature, letters or relevant documentation. There are many ways of interpreting this type of data (Byrne, 2001; Cohen and Daniels 2001; Smith 2003). As Byrne (2001) states these texts then generate themes, which communicate findings that reflect knowledge of the phenomena under study. To aid the analysis I have adapted Gadamer's four concepts, *prejudices*, *fusion of horizons*, *hermeneutic circle* and *play*. These four concepts will be used as sub-headings and illustrate how the analysis of the data was undertaken. I will incorporate the four suggestions by Cohen et al (2000) to assist in the analysis, which are 'immersing oneself in the data', 'data transformation or data reduction', 'thematic analysis', and 'writing and re-writing' (Cohen et al 2000, pg 76-81).

Prejudices

This concept refers to our preconceptions and pre-understandings of the sample we wish to study, for example what leaking urine means to these women in the study. The hermeneutic phenomenological approach to data analysis involves moving from the field of text, created by data collection, to a narrative text that stands alone for other readers (Ricoeur, 1981). This process is described by Cohen et al (2000) as *immersion*. Throughout the interviews, my initial familiarisation commenced when I started transcribing the interviews from Urdu into English, as this process required me to stay close to the data. My preconceptions or prejudices formed part of the initial interpretations and determine the languages used by participants and ourselves which is achievable through our presuppositions linked with historical character.

Fusion of horizon

The initial interpretations are based on initial horizons of understanding which in turn are based on prejudices. Heidegger describes this as aphorism, or in Gadamer's

term, a fusion of horizons. This represents a range of vision that includes everything that can be seen from a particular viewpoint. Understanding takes place when our horizons fuse with the object of interpretation to alter our own horizon and to extend the range of vision. Gadamer here is speaking of historical horizons in terms of time and culture, where he simply means that our past experiences will always influence the way we see and the way we interpret the horizons of others and ourselves. Gadamer determined that fusion of horizons occurs when our own horizon is understood in order to understand that of another. Therefore the act of understanding occurs when there is a conscious act of fusing two horizons, creating historical consciousness (Turner, 2003).

It is possible to take the concept of horizons and apply it to individual histories occurring in a given period, as with the women in this study. For example, fusion of horizons occurred at multiple levels throughout this study, in a to and fro movement. The concept of fear, of going against their religious belief, hope that this condition was treatable, and finally for many of these women to speak of their concerns, issues and worries regarding urinary incontinence. Gadamer explains that our horizon is something that moves with us, rather than something into which we move, adding that when we find ourselves in situations that we wish to understand, our task is to understand it further. This task is never finished, and becomes an infinite task of refining and extending our understanding of things.

Cohen et al's (2000) second stage of analysis can be applied to the fusion of horizons. This is a continuous process whereby we acknowledge our prejudices against the data generated.

Hermeneutic circle

There is no beginning or end to the hermeneutic circle. Our interpretation with this circle or continuous representations or interpretations allow us to revisit at any stage (Gallagher 1992 pg 58). Subject/object distinctions are not made within this circle, due to the active process of interpretations through the fusion of horizons, to ensure no background meanings are lost. An example of how this process could be applied to this project relates to the stories or narratives by participants themselves. Participants talked about their past or current experiences and those of their families and friends and related these to their religious beliefs, a movement between the whole (their lives) and the parts (Islam). Islam then became a part of their narratives, and a way of bringing together and relating experiences to a 'referential framework'.

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Therefore, within the hermeneutic circle, participants' narratives moved between the 'whole', the phenomenon under study to 'part', which became Islam.

This involved me in interpreting each 'word' against the whole sentence and vice versa to ensure authentic interpretations were made, as well as situating my own preconceptions and understandings against their narratives. Key words were copied from the original transcripts and pasted into another word document, to allow me to easily access ideas. This process allowed me to extract exact words spoken by the participants into headings which I had developed in the initial stages, and also allowed me to develop and explore further themes with participants. This process is described by Cohen et al (2000) as '*data transformation*' or '*data reduction*', which involves some decision-making on the part of the researcher concerning what is relevant and what is not (pg 76).

Cohen et al (2000) describe this process of coding as one that is used to break up the data into simpler, more general categories, and provide new insight for further interpretations, without losing sight of, or the meaning of *thematic analysis*.

Play

Gadamer's concept of play is used as a guiding concept to understanding. Burwick and Pape (1989) state the '*concept of play for Gadamer involves strategy predicated by the work of art...Instead of looking at the work as an object, one looks through it*' (p10). Gadamer argues that the concept of play allows us to acknowledge that the observer becomes intertwined into an event that they do not have control of and in which they cannot freely dispose of their normal horizons of experiences and expectations (Gadamer, 2004; pg102). This enables us to enter the circle with the text to create an understanding and interpretations made become unique, and create new horizons. The concept of play relates to this study, as the narratives and the stories of the participants took the study in a direction that they intended, issues and concepts emerged in their stories which I had not pre-determined but had become a part of their lived world, and their experiences.

The process of reading and re-reading the transcripts allowed me to become more aware what Muslim women were trying to convey. Engagement with the data in such a manner by listening to tapes, readings transcripts, referring to the field notes, allowed me to commence listing key ideas and recurrent themes (refer to appendix 10), which were continuously discussed within the supervisory meetings. Such

meetings proved beneficial as they allowed me to view themes that could be considered, as well as share my own reflection on the data generated.

This process of analysis is characterised by Cohen et al (2000) as the *final stage*, moving between two fields; one is the text that is produced through data collection and the second the narrative text. Using a hermeneutic circle as a means of interpreting data means that the smallest statements are considered in terms of the whole text in circular movements to allow for understandings. Interpretation can never be complete because the extent of detail that can be transcribed is limited both practically and theoretically (van Manen 1990). I became aware that the transcript was a representation of a particular event, rather than the actual event itself. Consequently, awareness of the nature of the transcript, sense of transparency and the strategy and assumptions are all used as the basis of analysis (Ritchie and Lewis 2003, pg 204).

All 41 participants' data was formatted in this way, which allowed me to draw together similarities and differences between them. Towards the end of this stage of analysis, all interpretations generated were brought together to answer the overall research question.

Participants' perceptions, views and beliefs were established in a written account of my interpretation of the themes identified. Six chapters have been dedicated to presenting these themes, which will identify how the themes and sub-themes emerged in women who had not sought help, and women who had sought help. The findings are viewed and presented within a creative synthesis of selecting exemplars and quotes from the narratives to illustrate the interpretation of the data (pages 139-210).

Feeding back the findings

Throughout the project, it was my aim to be as transparent about the study as possible. Therefore, I endeavoured to engage with my participants not only during the actual interview but also through other means.

Traditionally, the process of disseminating the findings of any research project has included presenting them to a target group, usually professionals working in the field of interest. However, Wolfram (1998) states that researchers ought to feedback knowledge into the community that facilitated the investigation in the first place. For this reason, I intended to feed back findings into the community in which the research

meanings proved beneficial as they allowed me to view themes that could be considered, as well as share my own reflection on the data generated.

This process of analysis is characterized by Cohen et al. (2000) as the final stage, moving between two fields: one is the text that is produced through data collection and the second the narrative text. Using a hermeneutic circle as a means of interpreting data means that the smallest statements are considered in terms of the whole text in circular movements to allow for understanding. Interpretation can never be complete because the extent of detail that can be transcribed is limited both practically and theoretically (van Manen 1990). I became aware that the transcript was a representation of a particular event, rather than the actual event itself. Consequently, awareness of the nature of the transcript, sense of transparency and the strategy and assumptions are all used as the basis of analysis (Fitzler and Lewis 2003, pg 204).

All 41 participants' data was formatted in this way, which allowed me to draw together similarities and differences between them. Towards the end of this stage of analysis, all interpretations generated were brought together to answer the overall research question.

Participants' perceptions, views and beliefs were articulated in a written account of my interpretation of the themes identified. Six chapters have been dedicated to presenting these themes, which will identify how the themes and sub-themes emerged in women who had not sought help, and women who had sought help. The findings are viewed and presented within a creative synthesis of selecting examples and quotes from the narratives to illustrate the interpretation of the data (pages 132-210).

Feeding back the findings

Throughout the project it was my aim to be as transparent about the study as possible. Therefore, I endeavoured to engage with my participants not only during the actual interview but also through other means. Traditionally, the process of disseminating the findings of any research project has included presenting them to a target group, usually professionals working in the field of interest. However, Williams (1995) states that researchers ought to feedback knowledge into the community that facilitated the investigation in the first place. For this reason, I intended to feed back findings into the community in which the research

was carried out, taking into account both the Muslim women and the MDT urology team.

I have been able to present the findings to the MDT urology team at the local hospital, who are involved in providing continence services. This became a way of representing Muslim women by 'providing a voice for the participants in the study'.

Muslim women who participated in the interviews were invited to a 'women's group' session at a local community centre study area, which took place in March 2008. These sessions are aimed at South Asian women with the aim of providing information on Maternity Services.

For the MDT urology team, oral presentations of the findings were presented, as well as written findings in the form of reports which were disseminated on 4th April 2008. The presentation formed a basis for a group discussion.

This process of feeding back the findings was not integrated into the findings, but did form part of the reflexive chapter (chapter 14).

Conclusion

This chapter has presented the methodology that has guided this study following the methods recommended. I have taken a hermeneutic approach which is consistent with in-depth interviews as a method of data collection.

The organisation of this chapter was presented in the format of an overall research design consisting of the considerations that are required to conduct any research project, i.e. the sample and the sampling strategy, advertising, and all areas of concern. The practical issues of the research have been presented to provide a clear account in relation to data generation and the data analysis process.

Reflexivity is one of the main considerations to be considered within a hermeneutic approach, which accounts for the quality, rigour and transparency; these issues have allowed others to note how I maintained each within a systematic data analysis process.

Initial data analysis began with Ritchie and Lewis' (2003) 'Framework' approach, and then was reconsidered using the four concepts of hermeneutics as proposed by

was carried out, taking into account both the Muslim women and the MDT oncology team.

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Gadamer and also drawing on Cohen et al's (2000) four stages of analysis. The initial 'Framework' approach proved to be too deconstructive for the theoretical approach I had taken, and did not allow my own thoughts to emerge with those of the participants.

In the next chapter, I have introduced the participants. Due to the large number of participants, all their narratives cannot be presented. I have therefore concentrated on the stories of ten women, to provide some background information into their lives. A full demographic table is presented in appendix five.

Chapter 5: Pre-Findings Chapter

Introducing the Participants

In the previous chapter, the methodological approach to this study was outlined followed by the data collection methods, and how the data was analysed using a hermeneutic approach.

Introduction

In this chapter, I introduce ten South Asian Muslim women who took part in this study; their narratives will be brief and concise. A demographic table is provided in appendix five, which covers the age, marital status, medical history, number of childbirths, country of birth, number of people per household, profession, identity and the interview length. As the sample consists of 41 women, I have selected only ten stories from women with varying age, and country of birth.

South Asian Muslim women

The personal stories of the ten women are outlined below. These stories are provided to situate them as individuals, or the 'parts' of the text (the participants), before relating them to the 'whole', as this is in line with the hermeneutic phenomenological approach taken. Ten randomly selected stories are provided in much more detail than the remaining thirty-one, due to word limit.

The ten stories are presented to provide an understanding of some of the circumstances they faced as Muslim women, as wives, as siblings, living in the Northwest of England. The first five stories are of those Muslim women who had **NOT** sought help, and the remaining five are stories of those women who **HAD** sought help through the continence services.

I have used pseudonyms, in order to provide an empathetic approach to the Muslim women in this study. My aim in this chapter is to highlight the individuality of each participant, as each is unique in their own right.

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The Setting

In England 40% of Muslims, live in London where they make up 8.5% of the population. There are also large numbers of Muslim in Birmingham, Manchester, Bradford, Luton, Slough, Leicester and the mill towns of Northern England (national statistics online, 2001). Many of the employees for the cotton mills were recruited from India, Pakistan and from the Asian communities of East Africa; therefore many resided in this regional area until the closure of the mills (Green et al 2005).

The census data was reviewed to gain an overview of the Northwest region. The data shows an increase in the number of ethnic minority populations by 5% in this area. An increase was also seen in the number of people unemployed, 51.4% of the ethnic minority population in the Northwest was unemployed, and this figure includes both men and women over the age of 18 years. Almost seven in ten (69%) Muslim women of working age were economically inactive (social trends, No3 2006). This is evident in the demographic data of the 41 South Asian Muslim women in this study, 24 participants were unemployed and six worked part time. Employment and education for this sample remained low as many participants stated that these were not a necessity, as Islam does not permit such acts. Socially participants were restricted in their movements, and contact from the wider society reduced. This was namely due to the family pressure to conform to cultural traditions that had continued for generations, where women are restricted.

In the town where this study was conducted, it was clear that there were very distinctive ethnic minority and majority areas. All participants interviewed and approached lived in predominantly Asian areas, where there were a number of mosques, Asian groceries, where neighbours communicated in the common language of Urdu, and where the characteristics appeared similar, i.e. clothing, values, practices, religion etc. This appeared to be a common practice, even when children were married they lived in close proximities if not in the same household.

Although integration with other communities was common among the younger British born participants, older Muslim women appeared to be happy in their chosen area of residence. This may not be similar to the rest of the UK; however this study is based in a town, a small town, a town where the Muslim population is high and increasing, a town these women called 'home'.

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Fatima's Story

Fatima is a 70-year-old woman, who had nine children, two of whom had died in early childhood. Fatima has been a widow for over 15 years. She still lives in the house her husband purchased when arriving into the UK. All seven of her children live in close proximity within a five-minute walking distance.

Fatima currently lives with her youngest son, daughter-in-law and granddaughter. Her youngest daughter recently moved in with her husband, due to refurbishing their own property.

Fatima arrived in the UK in the 1970's to join her husband, who worked in a cotton mill. She described herself as an Indian Muslim. Fatima had never worked. The reasons related to the number of children, poor health, and refusal by her husband. Prior to the interview, Fatima had printed off a list of her medication for me to see as she viewed me not as a researcher but as a trained nurse.

Fatima suffered from asthma, diabetes, arthritis and recurrent UTI's, which she felt 'disabled' her to carry out daily tasks, i.e. cooking, cleaning. Overall, she felt she could 'manage' and did not want to rely on others for help.

Fatima was unable to identify the length of time she has suffered from leaking urine, and this had now just become a part of her life. Urinary incontinence was the least of her worries, as she had many other conditions which she felt were more severe, such as asthma and diabetes, for this reason Fatima had not sought help. Fatima believed that it was due to her uncontrolled asthma that she had UI, as every time Fatima coughed she would leak urine.

Socially Fatima was restricted, because of her UI. The cold weather also made her symptoms worse. Her lack of sleep was also related to UI; Fatima stated she was 'lucky' enough to have been given a commode, which she placed next to her bed at night, as she would need to regularly toilet herself throughout the night.

Although UI placed considerable restrictions on Fatima, she saw this as a blessing. She stated that once she was up she would find it difficult to return to sleep; she would remain awake and pray the Quran, and worship her God.

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Aisha's Story

Aisha is an excitable person. Aisha was born in the UK, though her parents originate from India.

Aisha was married at the age of 18 years, to her long-distance cousin from India. Aisha did not have an arranged marriage, but stated it was a way for her to gain independence from her parents. Aisha has two children; one boy aged nine and one girl aged six. Her parents live in close proximity. Aisha states that families' living close together is normal within the Asian community. Her uncles, her grandmother and her cousins all live in the same area.

Although Aisha was born in the UK and had a chance of education, she refused this opportunity. She was not interested in education or a career but wanted her own family. As time has passed Aisha had desired to gain qualifications as all her brothers and sisters had graduated from university. Consequently, she was the only one without a degree. Aisha did not do well in her GCSE's and felt like a failure compared to her siblings.

Medically Aisha suffers from asthma and recurrent cystitis and thrush. Aisha is a smoker, although her parents were unaware of this.

Leaking urine was common for Aisha through her school years, but progressively worsened after having her children. Aisha usually manages her condition with tena pads that she purchases herself. Aisha's incontinence is made worse by her asthma or when she laughs or sneezes. She does not feel her condition requires medical attention and therefore has not sought help, as she would feel uncomfortable with the examination. She also considered it to be a normal part of childbirth.

Through the interview, Aisha became very angry about the lack of media coverage about the condition. She considered that if it is not promoted, people are less likely to seek help.

Habiba's Story

From the beginning of the interview until the end, Habiba appeared to be very serious with the issue of UI, although she was unable to maintain this whilst discussing other issues. For Habiba I was a nurse not a researcher.

Habiba is 50 years old. She was married at the age of 16 years. Her marriage was arranged without her consent. She describes this as having faith in her father, who is now deceased. She believed if her father had chosen someone for her then he would be suitable. Habiba's husband is 10 years older than her. They both originated from the same village in India, and therefore knew each other. Habiba has lived in the UK for 28 years.

Habiba has five girls, three of whom are married, and live within close proximity. Throughout her story, she made comments about her daughters and how 'proud' she was of them. Habiba stated that she had suffered from verbal abuse in her community due to giving birth to girls and no boys. She also stated that it was common for a Muslim man to leave his wife and marry again if she did not bear a son. Habiba felt lucky that her husband had stayed with her.

Habiba is the eldest daughter in her family, and had the responsibility to care for her younger siblings, due to which she was unable to work. Her father did not allow her to go to school for the same reasons. Habiba now has a part-time job, which she enjoys. Habiba works as a dinner lady in a primary school near her own house.

Medically Habiba suffers from asthma and general weakness. For Habiba the cause of leaking urine was related to her menstrual cycle, as she was more prone to leak large amounts of urine whilst menstruating. Coughing, laughing and exercising caused her to leak. Habiba was unable to define how long she had had this problem, but at the same time was very embarrassed to discuss it with a GP, and therefore refused to seek help.

Rashida's Story

Rashida is a 34-year-old woman, who migrated to the UK at a very young age. She was 4 years old when she arrived in the UK. Rashida migrated with her family to join her father who had lived in the UK for five years but who would visit India regularly. Arriving into the UK at a young age allowed Rashida the opportunity for free education, and currently she works as a social worker.

Rashida has been married for 18 years and has three girls, age 16, 14 and 8 years. She also had a stillbirth, which was a boy. A son was something she had longed for. For Rashida this tragedy made her feel 'depressed'; she only overcame this through the support of her husband. Her marriage had not always been good as Rashida

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suffered physical abuse in the early years. Rashida's mother-in-law, who is now suffering from dementia, lives with her.

Medically Rashida suffers from asthma, and obesity. She also had a hysterectomy after the stillbirth. Leaking urine for Rashida has been progressively worse over the years, but she was unable to identify the length of time. Rashida did not believe childbirth to be a cause of her UI, as all three births were caesarean-sections.

Rashida stated she would seek medical help only when and if she felt her UI was worse; and this would be her interpretation and no one else's. Rashida wore pads on a daily basis to manage leaking urine, however she did not feel it was necessary to seek help. For Rashida this procedure was as normal as 'brushing her teeth'.

Tanzeela's Story

Tanzeela is a 37-year-old woman who was born in the UK. Her parents originate from Pakistan. Although born in the UK Tanzeela describes herself as a Pakistan Muslim. Tanzeela describes her childhood as very strict. Tanzeela's parents would not allow her to wear Western clothing, such as jeans or trousers.

Even through her school years, Tanzeela had to wear a long skirt with loose trousers. After school, her parents expected her to change into the traditional Asian outfit and cover her hair with a scarf.

Tanzeela was married straight after her high school education was completed. Her marriage took place in Pakistan to her first cousin, who she did not know. Tanzeela has two children.

Tanzeela wished to go on further education after high school, but her father refused. She was able to work but only on a part-time basis. Due to her cultural upbringing she felt that educating girls was not appropriate, but feels lucky enough to have been able to seek employment.

Medically Tanzeela does not suffer from any problems, although her family history is vast. Her father suffers from heart conditions, hypertension, diabetes and asthma. Her mother also has diabetes and asthma.

Tanzeela has had UI for approximately 10 years. The condition was not an issue in the early years, as she felt it would just 'go away' but now she worries about the

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Tanzeela has had UI for approximately 10 years. The condition was not an issue in the early years, as she felt it would just 'go away', but now she worries about the

condition. Through the interview, Tanzeela felt that she had limited knowledge about UI and that if she had more information about why this happened she would consult a doctor. However, the doctor would have to be female as examination by male doctors was forbidden because of her religion. Although Tanzeela appeared to be emotional distressed due to leaking urine, she had not sought help.

Naila's Story

I was introduced to Naila during a health promotion session by a physiotherapist. Naila informed me that she was 26 years old. She appeared to be very quiet. She originated from Pakistan. Naila has lived in the UK for seven years and was married at the age of 15. Naila clearly remembers the day when she arrived back from school, very excited as her cousin was getting married that weekend. Naila's parents informed her on her arrival home that she was also getting married on the same day as her cousin. Her husband was a relative that had arrived from the UK to join in the wedding celebrations. Naila did not argue and agreed to the marriage.

As the interview progressed Naila disclosed her real age, of 24 years old. She had four children all of whom were at very similar ages. Naila cried throughout the interview. She stated that she would run around after her children all day, and she had no peace. Naila's husband has his own company, but does not help around the house, as he believes this is a woman's job.

Naila felt isolated; she did not have any friends and was unable to speak to anyone outside the house. Her support was her sisters-in-law who were all in similar situations. Continuing with the interview proved difficult as Naila would cry, but she requested that she just wanted to voice her opinions. The interview continued.

Naila does not suffer from any medical conditions. She has however been under the care of a physiotherapist for 2 years for urinary incontinence. Naila leaks urine when she lifts heavy weights. She does not feel this condition is related to her number of births. Naila has been advised to commence pelvic floor exercises, although she feels she does not have the time or the energy to complete them. Naila initially decided to seek help through the advice of a hospital interpreter, and was referred to the continence services.

Shahista's Story

Shahista is a 54-year-old woman, who originates from Pakistan. She has been living in the UK for 25 years. Shahista was married in Pakistan to her husband and they both migrated to the UK. Shahista did not mention her husband throughout the interview, and would avoid answering questions about him. I was therefore unable to establish whether her husband was living.

Throughout the interview Shahista's daughter was present, although Shahista spoke English. Shahista has two boys and two girls, and three grandchildren. Her family live near by: her eldest daughter lives in the block of houses in front of her house and the other daughter lives two doors away; both her sons live with her with their wives. Shahista does not have any other medical conditions. She has been suffering with UI for nine years.

Shahista first decided to seek help about four years ago. She approached her GP who referred her to the hospital services 'continence care'. Her experience at the hospital by one of the doctors was inappropriate. Shahista had to undergo an urodynamic test, however she was unable to control her bladder and the test was discontinued. Shahista stated that the doctor became verbally abusive and stated 'she was wasting her time', since then she has refused to seek help.

Through the persuasion of her eldest daughter, Shahista decided to go back and seek further help, but still does not feel satisfied with the services she has received. She has been waiting two months to see a physiotherapist.

For Shahista I was a nurse, who she expected to push her case forward. Shahista requested that I spoke to the nurse specialist and the physiotherapist or the consultant.

Ghazala's Story

Ghazala is a 76-year-old woman, who is a widow. She lost her husband to ill health. Ghazala arrived into the UK 36 years ago from Pakistan to join her husband. She has five children. Since the death of her husband, Ghazala feels things have changed for the worse. Ghazala's family have always lived in one house, but recently her son and daughter-in-law moved out, Ghazala feels that if her husband was living this would never have happened.

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Ghazala's Story

Ghazala is a 70-year-old woman, who is a widow. She lost her husband to ill health. Ghazala arrived into the UK 35 years ago from Pakistan to join her husband. She has five children. Since the death of her husband, Ghazala feels things have changed for the worse. Ghazala's family have always lived in one house, but recently her son and daughter-in-law moved out. Ghazala feels that if her husband was living this would never have happened.

Ghazala has never worked outside the family home. She believes a woman should not work and men are the providers. This tradition has been maintained in her family, as none of her daughters or daughters-in-law have ever worked. Throughout the interview, two of Ghazala's daughters-in-law were present for the purpose of communication. Ghazala only spoke Punjabi. Although there are similarities between Punjabi and Urdu I was grateful that they were present.

Medically Ghazala suffers from asthma, diabetes, hypertension and UI. Urinary incontinence for Ghazala was not a condition she would need to worry about as she felt old age was the cause of this problem. However, on the request of her daughter in law Ghazala decided to inform her GP, who referred her to the continence services. Currently Ghazala was prescribed oxybutynin (treatment for UI), but she has stopped medication, without informing the specialist. Ghazala feels neither the medication nor the pelvic floor exercises to be helpful. Although Ghazala does not want an operation, she feels she has now come to the end of her life and no medication or operation is going to give her a better life.

Roshin's Story

Roshin is a 28-year-old woman born in the UK. Roshin was married after high school to her cousin in Pakistan who she did not know. Roshin has been married for 12 years now and had three sons, which provided her with a sense of self-worth, as boys are thought of more highly than girls.

Her parents and her husband had refused to allow her to access further education or work outside the family home; as a Muslim girl should not take up such acts.

Roshin's husband works as a taxi driver. Roshin feels her husband came into her life as an 'angel', as she began to live her life as a Muslim woman should. Roshin now wears the Hijab, and is also hoping to go to Mecca on a pilgrimage this year.

Medically, Roshin suffers from an overactive thyroid, cholecystitis, asthma and UI. Roshin has suffered from UI for about 4 years, mainly after the birth of her second child. She has never really paid any attention to her UI, as her other medical problems outweighed this condition. Now that Roshin has sought help, she is awaiting an operation to correct her condition.

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Roshni's Story

Roshni is a 58-year-old woman born in the UK. Roshni was married after high school to her cousin in Pakistan who she did not know. Roshni has been married for 15 years now and had three sons, which provided her with a sense of self-worth, as boys are thought of more highly than girls.

Her parents and her husband had refused to allow her to access further education or work outside the family home; as a Muslim girl should not take up such acts.

Roshni's husband works as a taxi driver. Roshni feels her husband came into her life as an 'angel', as she began to live her life as a Muslim woman should. Roshni now wears the Hijab, and is also hoping to go to Mecca on a pilgrimage this year.

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Hameeda's Story

Hameeda is a 46-year-old woman who migrated from Kenya at the age of 15 with her family in search of a better life. They all settled in the East London area, where she worked at one of the airports as a security guard. Hameeda had to leave work to care for her sick mum who died 10 years ago.

Hameeda was married at the age of 38 years, and moved up to the area to be with her husband and his family. She did not want to marry but through the request of her dying mum she agreed.

Since moving to the East Lancashire area, Hameeda feels trapped and isolated in her own house. She has no friends and does not feel like leaving the house. Her husband is out most of the day with his relatives, and only returns home for meal times. Throughout the interview Hameeda would cry and be very apologetic, but at the same time request to continue with the interview.

Medically Hameeda has been diagnosed with depression, angina, diabetes, obesity, oedema, and urinary incontinence. Hameeda was informed that she was suffering from UI due to childbirth, a concept that did not make sense to her, as she had no children. Hameeda was unaware of why she had developed UI, but felt fortunate enough to have been under the care of an uro-gynaecologist.

Summary

In this chapter, I presented the stories of ten South Asian Muslim women who took part in this study. These women raise and indicative of the key issues to emerge within all the women's stories. The stories are briefly described to provide a context for the thesis and to situate the participants in the study.

In the next chapter, I consider the development of issues that have emerged through my interpretation of the data.

Hamada is a 45-year-old woman who has been married for 15 years. She is a housewife and has three children. She is currently working at one of the shops in the area. She has a good relationship with her husband and is a very caring mother.

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Since moving to the East, Hamada has been working at one of the shops in the area. She has a good relationship with her husband and is a very caring mother. She is currently working at one of the shops in the area. She has a good relationship with her husband and is a very caring mother.

Medically, Hamada has been healthy. She has no chronic diseases and is in good health. She has no chronic diseases and is in good health. She has no chronic diseases and is in good health. She has no chronic diseases and is in good health.

Summary

In this chapter, I presented the results of the study. I discussed the findings and the implications of the study. I discussed the findings and the implications of the study. I discussed the findings and the implications of the study.

In the next chapter, I will discuss the limitations of the study and the future research. I will discuss the limitations of the study and the future research. I will discuss the limitations of the study and the future research.

Chapter 6: Findings

'Me, my family and I'

Introduction

The previous chapter introduced a selection of the participants and their stories. This chapter and the following five chapters are dedicated to the themes and sub-themes identified through the participants narratives.

Chapter six and chapter seven present the fundamental aspects of the participants lives, which includes the family and their religion. Chapter eight, nine and ten explore the issue of urinary incontinence. The normalisation of urinary incontinence is explored, together with culturally taught behaviour that restricted many seeking healthcare. Finally, chapter eleven considers some of the reasons that fourteen participants out of forty-one sought help.

This chapter will begin with exploring participants' narratives, practices and beliefs that have continued from one generation to the next and which may be difficult, if not impossible, to change. The title of this chapter is 'Me, my family and I', as South Asian Muslim women in this study stated that their life and being was centred on their families. Through the narratives participants related specific issues back to the family. These can be listed as follows: higher status of males, restricting female movements, and care of others. The family is the foundation for these communities, as will be seen throughout this chapter. The impact of the society is also an area which I intend to cover in the sub-theme titled 'that's what they say'. The society in which many resided also influenced their behaviour. Migration has also played a large role in cultural views, practices and values, although there are also clashes between communities, for example Muslim Indian and Muslim Pakistani. This concept of migration will be included in the sub-theme titled 'who cares what others say', within which I will explore British-born Muslim participants' views and those born in the South Asian countries. The family, the community and the society these women resided in all impact on their view of life and how they react to each situation in their life will be illustrated.

'That's what they say'

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'That's what they say'

The influence of society on the lives of the participants was apparent. All the participants lived in predominantly Muslim areas, where many dressed the same.

spoke a common language, and had similar views, values and carried out similar practices.

Participants were asked to describe culture and identify some practices that they deemed essential. The term *'they'* in this title refers to the wider society that these women resided in which many described as their larger families:

'Culture... that is the people that live around you... like for example we have a lot of Asian families here, everyone is the same, same religion similar clothing, same God, it is nice it's like being home in Pakistan. People are very close to each other, we look out for each other it's nice' (Farhat, 46 years old).

All participants in this study lived in predominantly 'Asian areas'. Being around people with similar beliefs, similar characteristics and faith was an important factor for them:

'This area here is full of Muslim people. We are all the same ... It is nice though like in ramazan when we all get together it's nice. People look out for each other' (Nazia, 54 years old).

The benefit of living in such a community for many was a way of protecting and continuing cultural practices:

'Yeah they are that's what makes you belong to a group if you did something that was not a norm then you are an outcast you don't fit in you have to conform' (Arifa, 37 years old).

The impact of culture and society on the lives of the participants was seen as a positive factor, as many felt they had support. A sense of 'togetherness' was noted in their narratives. In its basic form, culture is defined as 'state of manners, taste and intellectual development at a time or place' (Combined Dictionary and Thesaurus, 1999). In other words a set of beliefs and practices that are passed from one generation to the next, which are examined, continued or disregarded.

Participants' perception of culture was based on their upbringing. Culturally acceptable and unacceptable behaviours, and the Asian/Muslim views, practices and opinions all influenced their behaviour and their lives. The term culture has been

spoke a common language and had similar customs and practices.

Participants were asked to describe culture and to explain why it was deemed essential. The term 'they' in this question was used to refer to the women residing in which many described as traditional.

Culture is the people that live around you. The things that you do. In Asian families here, everyone is the same. They all have the same values. It is nice to live being home in Pakistan. There are many things that you look out for each other. It's nice to have that.

All participants in this study lived in predominantly Asian communities. People with similar beliefs, similar characteristics and similar backgrounds lived in them.

This area here is full of Muslim people. We are all Muslim. It is nice to be together when we all get together. It's nice to have that. (Participant 54 years old).

The benefit of living in such a community is that you have a strong sense of continuing cultural practices.

Yeah they are that's what makes you belong to a group. It's nice to have that. It was not a norm then you are an outsider. You don't belong to the group. (Participant 37 years old).

The impact of culture and society on the lives of participants was a positive factor, as many felt they had support in their communities. In their narratives, in its basic form, culture is defined as a set of values, beliefs, and intellectual development at a time or place. It is a shared experience and a common (1999). In other words a set of beliefs and attitudes that are passed from one generation to the next, which are examined, combined, and changed.

Participants' perception of culture was based on their own experiences. It was acceptable and unacceptable behaviour, and the participants who were not in their opinions all influenced their behaviour and their lives. The way culture was

used loosely to refer to people of different ethnicity and nationality. For these participants it was much more than that. For those born outside the UK, the term culture also incorporated such materialistic items such as clothing and food:

'Culture is what we have been brought up with, our clothing, the way we speak our food, where our parents have been brought up, that is home where our parents homes are back home in India or Pakistan (Abeeda, 57 years old).

British born participants felt they had to lead a double life for they had to learn to live the traditional Asian way, and conform to the more Western culture.

'My parents never forced us to wear Asian clothes or anything, I was allowed to go college and university, but I was not the studying type. My parents let us do what we wanted as long as we lived the way a Muslim is suppose to [...] pray don't cause anyone harm things like that. They met us half way, I still wear jeans and things and my husband prefers me in Western clothes. I did learn about our religion and yes went to mosque I pray too; really, I have the best of both worlds' (Ameena, 27 years old).

'Culture to me is the way we behave in different situations ... like I would act differently with my friends than at home or with my parents we have been customised to act differently in differently situations. Sometimes I feel like I am living a double life, I want to be like everyone else [Western culture] and then I am aware of living a life like a Muslim too. For example, in British society or at least when I was in school when you got told off you would look down and the teachers would say 'look at me when I am talking to you'. Whereas if you looked at your parents when you were being told off they would say 'look down don't you have any respect for your elders'. (laughs) it's like having two different personalities you wouldn't act the same in front of your parents as you would in front of just say like teachers. Culture is what you have been taught from a young age from your parents it is the way we learn to live with each other in our society' (Noreen, 26 years old).

British born participants in this study all voiced similar concerns, and described culture as a 'learnt behaviour' including all behaviours learnt through socialisation (Kirby et al, 2000. pg 25). These participants praised their parents for continuing with their traditional Indian/Pakistani cultures in a Western society, which they were alien too.

'The ways we have been brought up, I honestly believe our parents have done a good job, coming into a country they didn't know anything about. Bringing up their children in this country for them was probably a struggle especially within the language barrier. They tried to give us the traditional Indian culture as well as bringing us up as Muslims too. I think they have done quite well' (Saleema, 35 years old).

Cultural practices and accepted behaviour within the Asian communities for participants was important as this allowed them to live in those societies, where

want loosely to refer to people of different ethnicity and nationality. For these participants it was much more than that. For those born outside the UK, the term culture also incorporated such materialistic items such as clothing and food.

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Cultural practices and accepted behaviour within the Asian communities for participants was reported as the allowed them to live in those societies, where

religion and culture are regarded as the two fundamental components that bring people together. For many participants Islam was not just a religion but also a culture through which practices and norms are handed down from generation to generation. This was explained clearly in Saleema's narrative:

'Well I reckon religion and culture play an equal part and they work together. Without the culture, I do not think you are following the religion correctly. I do not think they are the same no, but I do think they link in somewhere. I don't think without culture ... I think religion is the foundation of culture cause if there wasn't a religion there wouldn't be a culture I think religion is made up of different cultures but um ... I do think they are linked with each other definitely. I think we act the way we do through the stories of our prophet, the way women in them times lived their lives, what is right and what is not, you know what I mean, but we have to understand that times have changed. That doesn't mean we shouldn't continue with such practices um its more like we continue but change for the better, like work education and things (Saleema, 35 years old).

Traditional or cultural practices and beliefs that have continued for generations are unlikely to change. Through the interview process participants identified where such practices originated from and why they are continued.

'My parents have kept up all the traditions they came with to this country so they wanted us to live their way and I would expect my kids to live the same way. Traditions they just carry on don't they I mean you cannot forget your roots. We can say we say we are all modern and open about things but you never really are there will always be something that your parents teach you that you teach your kids and so on. I am because of my parents I believe they have taught me how to behave in situations and things, which is a good thing. At the end of the day what matters the most to me, is me my family and I' (Aisha, 28 years old).

One belief that has continued across generations is related to Muslim women giving birth to a male infant. When a woman gives birth to a male infant she is more likely to be thought of highly than a woman who gives birth to female infants. Older Muslim women are more likely to hold such opinions than compared to younger Muslim women. In pre-Islamic times, a female was deprived of the most basic human right 'of life'. The practice of female infanticide was widely practiced among many and was referred to as a WA'd (Quran, 81:89). Islam forbids such practices and is highly critical of the attitudes allowing parents to reject their female children. Although infanticide is outdated, many still believe that men have a higher status than women (Benner 1996; Abu-Lughod 2004). This is not a religious belief as the Quran states:

'And they [women] have rights similar to those [of men] over them...' (Al-Baqara, 2:228, Quran).

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In other words women are equal to men in the sight of Allah in terms of her rights and responsibilities (Barlas 2002, pg 139-149). However gender inequalities and superiority of men is commonly seen within the Muslim culture, for example a Muslim woman who gives birth to a boy is thought of more highly than one who gives birth to a female.

'No brothers ... (laughs) Bet your parents wished they had boys, all you girls are going to leave them, I feel sorry for them. Do your parents not mind you working, I suppose with five girls you would have to work. They must be Westernised, but you are Indian right, so it is different for you lot ... well, we are pure Muslims, and follow a strict path. But you lot don't, and that's where your parents allow you to go out the house' (Ghazala, 76 years old).

The above quote also illustrates the practices that many communities still to date continue. For example, not allowing girls to work and maintaining a cultural division between similar religious groups Indian Muslims and Pakistan Muslims. Although the clash of cultures or countries was not apparent in many participants' narratives, it was clear that all participants in this study returned to the Islamic culture rather than conforming to the Western culture. The importance of religious practices and customs were voiced throughout the narratives, whether the participants were born in the UK or outside, there was a strong sense that the religious aspects throughout their lives were maintained, continued and practiced.

'Who cares what others say'

Such cultural practices were regarded as important by many of the participants in this study as they believed it was related to their religious practices. For example, many felt that it was culturally unacceptable to allow Muslim girls to work outside the family home. The problems were that it would involve the mixing of opposite sexes, regarded as a forbidden act, as well as a cultural belief that men should provide for their women:

'A Muslim girl should not work outside the house, this is not right and Islam says so. Work, you must be joking. I have never worked in my life ... never needed to work. My husband has always kept the family going. Plus also girls should not work. Why should they [daughter's and daughters in law] work we have everything in the house. Muslim girls should not work' (Ghazala, 76 years old).

'I have never worked because my dad didn't want his girls to work, and my husband said no too. I also have a big sister, who lives in America with her husband and two daughters. She does not work either because my dad did not want her too. The boys went to college and work. Do you work? [Question to myself ... yes] 'It is because you

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are India, Pakistani girls should not work. Girls don't need to go and find job' (Sofia, 37 years old).

Traditional expectations that women should remain in the home, were portrayed as being part of the Islamic faith. Islam does encourage Muslim women to stay home and look after their families. However, if a woman chooses to work Islam does not restrict her; she may do so with the permission of her parents or husband (if married) (Al-Misri and Keller, 1998).

'I wanted to work after I got married so I asked him [husband], but he refused and said he is not going to live on his wife's wages and he can provide for me. I still try sometimes hoping he will give in, but so far no luck' (Salma, 26 years old).

Such practices were also imposed onto their children. However due to the influence of Western culture many of their offspring refused to accept such practices. Dale et al (2002) in their study found younger women were more able to make a distinction between tradition and religion, thereby making it acceptable to take paid work whilst still being a devout Muslim. Indeed some participants, especially those who worked themselves or desired to educate their offspring, felt that there was no conflict between being a devout Muslim and working outside the home, and that religion and tradition should not be confused:

'Nowhere in Islam does it say a woman should not work' (Ameena, 27 years old).

Others encouraged their children to seek employment and further education:

'I know but I didn't go out to work because it was not right for girls to work. My children all work and go to university too. But in my days this was not done' (Shagufta, 54 years old).

For many seeking paid employment was only considered on a temporary basis, due to the financial hardship they encountered through the upbringing of their children, redundancy, providing for families abroad, and paying off debt. This was mainly encouraged by their partners, even though their parents had not agreed with such an act:

'My mother also says a woman place is at home should not go out or work (pause). I have 7 children and my husband cannot work all the time so I work too ... or did work,

but at home, I used to sew clothes for others ... it is good because I worked and could also help my husband with the money things' (Farhat, 46 years old).

In this study, age was not a dependant factor that determined this belief. Younger and older participants held similar views but generally, the belief that Muslim women should not seek employment was an accepted belief often justified with reference to Islam. These views were similar to those around educational opportunities: only one participant in this sample had graduated from university. For others the opportunity did not arise due to parental or financial circumstances.

'As girls we were told to stay at home and learn how to cook and clean things like that. My parents could not afford to send us to school, I remember my mum saying boys should be educated not girls because girls are someone else property. They leave home and go to someone else whereas boys stay with their parents (Shagufta, 54 years old).

'I did not go to school; because girls should really not go ... my parents did not agree. I would not argue with them, none of us went to school my parents could not afford to send us. Plus is there any point for a girl to be educated, not really because they are someone else's property (Nazia, 54 years old).

Educational opportunities for participants in this study varied. For those born in the UK it is mandatory to attend education until the age of 16 years. This, however, identified further problems as many then wanted to enter further education:

'I asked my dad if I could go to college like the other girls but he always said no because I am not his and that I belong to someone else and should ask him. I remember asking my then going to be in laws and they totally refused (Khalsoom, 26 years old).

'I wanted to go college and things but dad didn't want me to go ... I don't know. I did not want to argue with him ... dad is very strict and pious Muslim, he said our girls should not be going out to college and work. It is wrong. I got married as soon as I finished high school, I did not even go and get my results (Fozia, 26 years old).

If these women had their own income, they would not be providing for their own parents but their in-laws. For such reasons many women did not have the opportunity to gain education or even employment. These above quotes also reinforce the fact that men are thought of more highly than women, in terms of education. Parents were reluctant to educate their girls who eventually would leave their home and live with the husband's family.

but at home, I used to sew clothes for others ... it is good because I worked and could also help my husband with the money things. (Farhat, 46 years old).

In this study, age was not a dependent factor that determined this belief. Younger and older participants held similar views but generally, the belief that Muslim women should not seek employment was an accepted belief often justified with reference to Islam. These views were similar to those around educational opportunities: only one participant in this sample had graduated from university. For others the opportunity did not arise due to parental or financial circumstances.

As girls we were told to stay at home and learn how to cook and clean things like that. My parents could not afford to send us to school, I remember my mum saying boys should be educated not girls because girls are someone else's property. They leave home and go to someone else whereas boys stay with their parents (Shahana, 54 years old).

I did not go to school, because girls should really not go ... my parents did not agree. I would not argue with them, none of us went to school, my parents could not afford to send us. Plus is there any point for a girl to be educated, not really because they are someone else's property (Nasir, 54 years old).

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For those born in India or Pakistan, education was not a requirement or necessity. Education is not free in these countries; therefore educating girls is not a common practice.

'In our country it was hard because I came from a small village where we didn't get the education like you lot do here. My parents were farmers so we were very poor in Pakistan. Men in many families get the chance to go to school and work but girls it is different all together [...] it's different because the boy stays at home and we have to leave, that is just the way things are for us' (Nazia, 54 years old).

Participants that had migrated from other parts of the world all had brought along their cultural beliefs and practices to the host culture. Such practices continue to be passed through generations and preserved as their 'identities'. Adapting the Western culture can be daunting for people especially if their beliefs, practices and views on life are different.

Many participants, especially those born outside the UK, have a strong sense of belonging to a community and conforming to such behaviours. For these women continuing traditional practices was more important than for those born in the UK.

There were clear differences between participants in this study. At one end there were those who had a sense of 'being accepted' that was very important; what their wider communities thought influenced them immensely:

'I am a Pakistani and I follow what other say and do, like the clothes I am wearing are traditional Pakistani clothes you do and follow what others have done in the past cause that is believed to be right you try and fit in' (Sadia, 27 years old).

'What people say matters to me a lot. What other people think ... I mean if I am at the doctors every week I'm sure people would start questioning what's wrong. People do start making stories up, I mean I was sat in the GP surgery a while ago now with my youngest child and a woman that lives near by said to me that this other woman always comes to the doctor and that she thinks she has some kind of disease. So people do start talking I wouldn't be able to cope with that' (Farzana, 31 years old).

At the other end of the spectrum, there were those women who did not bother with the wider society.

'I am a single mum and its not good [...] a woman living alone with four children this society is very bad and looks at you bad [...] a woman they say cannot live alone and should not, but that is their problem not mine. I have made a life for me and my children these men do not like it because they cannot see a woman make her own life. People in our society are all the same, no one asked why he [husband] divorced me; it was because he got married to a White woman, and she told him too. However, no one will blame the man it is always the women. I do not have time to

worry what others say, who cares, these people that point their fingers at others tend to forget what is happening in their own houses' (Hameeda, 46 years).

'Of course you think what would others be thinking about you and Asian families all talk about each other (pause) we keep ourselves to us don't interfere with others. I let my children work because they have to learn to stand on their own feet; they have friends they go out. I know they would not do anything wrong, I trust my children. If you keep them locked up that is when things go wrong' (Khalida, 42 years old).

All the participants in the study felt that their own cultural upbringings were Islamic orientated. However, there was clear disagreement between those born in the UK and those in the South Asian countries, as both groups insisted the cultural practices of the other were not religiously based. The following illustrates the differences and similarities between those originating from the South Asian countries and those born in the UK.

For those born in the South Asian countries arriving into the UK was one of the hardest tasks they were faced with, as many felt that teaching their children appropriate cultural and religious behaviour was a struggle. Keeping them from Western influences was especially problematic:

'As our parents were very protective over us, we stayed in the house, did exactly as they wanted. I suppose I tried with my children, but it is hard. Not being in our own country, it is different here. You children that are born here mix with others and have lots of friends boys and girls. You do not hide things. My daughter in law is from Pakistan and she does not like my son talking to other girls, because she thinks he is having an affair, but she does not understand they are just friends at the end of the day. They have so many arguments; I just shut my ears now. She will never understand ... I suppose I use to think like my daughter in law. Over there girls are not allowed out the house, some girls were lucky they could go to school' (Farhat, 46 years old).

'When I came here I couldn't believe it, I saw on telly that people don't live like Muslims here. You see girls that wear jeans and are Muslims like us. We should not wear these clothes [...] Yes I would let my girls wear jeans; there is nothing wrong with what you wear as long as you don't forget your Islam' (Naila, 26 years old).

Participants born in India or Pakistan felt they lived life as Muslim women should. They viewed Muslims born in the UK as 'disrespectful' and people who have 'forgotten their religion'.

Participants born in the UK had all tried and experienced Western life. Some continued with some of these aspects such as wearing jeans, and accessing employment and education.

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'I suppose being bought up here is different, you see things differently and you mix with other people from different backgrounds and you want to do what they do or at least experience it you know. Like I said, leading a double life, I mean its wrong but sometimes these things have to be done right. You want to know how others live' (Hajira, 21 years old).

'Well when I was younger my dad use to be very strict but as time past he doesn't care well he does I mean like he wouldn't let us wear jeans or things like that but with my kids and my nieces and nephews he is different' (Arifa, 37 years old)

For those born in the UK, the view of Muslims born in the South Asian countries was a 'cover up' of their deeds. By this many of the British born participants referred to stories they had heard through friends and family living in India or Pakistan.

'Mum always says they live like 'true' Muslims there and we don't here, she always praises them for some reason...I've heard my parents and my husband say or she had a abortion and they did this, god half the things we wouldn't even dream of doing here' (Aisha, 28 years old).

Others felt that those migrating from Islamic states felt superior to them, although they believed that, in reality, the opposite was true.

'I think children born here have lost respect for their parents ... Suppose the only difference is we don't hide things' (Nadia, 37 years old).

Although clear differences were seen, there were also similarities, which consisted of respect and care of elders, care for family and obeying the husband. However both groups felt that the other did not consider such practices.

'Very different. We would not answer our parents back, but here you lot even swear at your parents. When our parents told us to do something we did it straight away but here you ask so many questions so we might as well do it ourselves (pause). I think children born here have lost respect for their parents but over there we would never even sit in the same room as our father out of respect' (Khalida, 42 years old).

'Yes very big difference children here don't respect their parents, and don't have respect for their elders. It is wrong a Muslim girl should not behave the way these young people act ... I think it is the same our children are born in Britain so they learn to live differently and they think that is better for them' (Farzana, 31 years old).

British participants also voiced similar views.

'Oh god, do not get me started on that. My mum still says girls over there are so decent, they don't ever answer anyone back they do as they are told etcetera but do you know my cousin has married a girl from India and the stories she tell us about the girls over there are just disgusting. Maybe the only difference is that we do not tend to hide things whereas what they do is behind closed doors I do not know. We respect our parents more than they do' (Nadia, 37 years old).

Through my interpretation, I found there not to be any differences between the two groups, as both groups continued with cultural traits taught to them as young children, although many were oblivious to this fact. Religious practices and views appeared to be similar between the two groups.

What was clearly of importance to both groups was the concept which I have termed 'Me my family and I'. The impact of the wider society was an influential factor, but not of such great importance as their families.

'Me, my family and I'

The family is the foundation of Islamic society. The security and support Islam provides is greatly valued and seen as an essential part of family life and spiritual growth. Karn et al (1999) identified that the family is not a social preference, but a strong foundation of a social infrastructure (Cuddihy 1999). Participants repeatedly stated that their family was their main priority in life after their religion:

'Family is very important to me, without my family I wouldn't be anywhere, nothing takes priority over it, but Islam and worshipping Allah. You have to think of them first and then yourself' (Naila, 26 years old).

A Muslim family is an extended family, normally with three or four generations within its circle. It was apparent in the participants narratives that the structure of their family was of great value, and a treasured aspect of their lives.

Muslim women's status in South Asian families is highly determined by the family structure. Through the narrative and stories, it became evident that after religion the health of their family members was as much of a concern as their own health. Caring for and providing for their families, children, husband, in-laws was more important than looking after themselves:

'We are women and as a woman it is our duty to be looking after people, to be nurturing, to nurture children. As women we have been socialised from the time we are young that this is what we should do, look after our children and husbands and his family' (Ameena 27 years old).

'Well I would like to think it is very important but I don't think I take that well care of myself cause of work and family. Yeah but different responsibilities like in the morning I have to get the little one dressed, you see they are all at different schools I have to drop everyone off then take myself to work cook and clean the house. So at the end of the day I don't have time to think about myself so I'm very tired so I just collapse and then its start all over again in morning' (Zarina, 39 years old).

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'As a woman you have to do a lot of things like look after your children, your husband the house and many more things, you don't have time for yourself, and then when you become old you think like I am old now why didn't I do anything about it then. But I just didn't have time then' (Tayiba, 76 years old).

In the Islamic societies, it is common for children to look after their elderly parents and to live with them for as long as possible. Many older participants resided with children and considered themselves as dependent on them. Omeri's (1997), study relates to the importance of the role of caring for elderly family members, as Muslim communities regard this as an act of pleasing their God. The views, advice and opinions of elders are regularly sought in an attempt to show respect to those considered wiser. All participants implied that whatever their elders requested of them, they did without any argument.

'It does matter to me what my parents think and of course my husband if my parents and husband think something is wrong then they are only saying it for my benefit' (Arifa, 37 years old).

'Respecting your parents is a must in Islam. I do not know if you are aware but there is a saying, 'the gates of heaven are at your father's feet and heaven is at your mothers'. You hurt your parents and disrespect them, you hurt God' (Fozia, 26 years old).

The close proximity of the Asian families was common in this study group. Participants either lived in the same household as their husband's extended family or near by.

'We all live next to each other. In this house there is me, my husband, my mother and father in law, my three children. Next door, this side is my eldest son with his wife and two children and across the road is my daughter with her husband and three children' (Nazia, 54 years old).

The benefit of living within close proximities to the extended family was related to 'support', *'I don't need to rely on anyone else, all my family are around me'* (Sobia, 58 years old). However, a lack of privacy and independence was reported as a negative affect of living with the extended family:

'My uncle doesn't let us do anything, he always says girls should stay home, if they go college they get corrupt and do things which we shouldn't do ... everyone listens to him. I would not even sit in front of him. My father in law is a horrible man. I cannot do anything, I feel like I am locked in this house. When I came here the first time, we lived with the full family. I use to be ignored and things by him. Once my friend rung and he told me not to speak to her and took the phone and put it down' (Naila, 26 years old).

Only younger participants voiced this in their stories, and showed a preference of the Western view of the nuclear family. For older participants this was clearly unacceptable:

'These girls that come from Pakistan are just like that ... well they don't understand we all live together. We have two houses this one and the one next door, so we have eight bedrooms altogether. She wanted her own place. So I had to let him go. Oh well that's the way things happen. They still come over but its not the same, my son does not look happy. We are all living in one place and he is living somewhere else now' (Ghazala, 76 years old).

As well as respecting the views of elders, participants stated the views and opinions of their husband were as important as their parents. Not respecting their husband was a grave sin; such an act in Islam that would never be forgiven. Many referred to this as a learned behaviour, something they had seen their own parents do:

'Whatever he says I do, I don't want there to be any problems. My parents have always told me to do and listen to whatever he says' (Farzana, 31 years old).

Many of the participants in this study had had arranged marriages. It was common cultural practice to marry into their own families, and marriages usually took place between first cousins. However, as this could mean the bringing together of two very different cultures and could lead to conflict:

'No not really when my husband came into this country we had a lot of arguments I suppose in a way yes it did affect me. He came here with the thoughts from back home that a woman should do this and not that. It was hard but I think gradually he has changed and yes for the better I mean you cant live the way they do over there its impossible' (Aisha, 28 years old).

'He came here we did not get on, he wanted me to do so many things. I have learnt now this is the right way. I use to be like you wear jeans and things, but now I wear the hijab ... he wanted me to wear the hijab ... well sort of. He did not like me wearing jeans and things. Now I am so glad I have come onto the right path ... yes I have started to pray five times a day I started covering my body and I am happy now. I did all the messing around, and mashallah look at me now I am happy more than I ever was' (Roshin, 28 years old).

Some women underwent physical and psychological abuse by the hands of their partners, but felt unable to voice their concerns as patience within the Islamic view was regarded of as importance. Women felt their silence was considered to be of personal benefit, as their God would reward them.

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'I can't do anything without his permission. How can I, no matter what I say I cannot hurt him, I don't want to go to hell, god will never forgive me ... god is watching and I will be rewarded if not here then when I die' (Hameeda, 46 years old).

Therefore, many of the participants obeyed commands made by their husbands.

'Women should always obey their husbands no matter whether it is right or wrong; women should stay at home look after their husband and kids. A woman should not go out to seek employment a man should always provide for women. Women should not mix with men in the same environment, especially if they are not related to one another ... god do you want me to carry on' (Ghazala, 76 years old).

This quote taken from Ghazala's narrative indicates that such practices continued across generations. However according to the religious tenets of Islam, and as stated by the prophet Muhammad (saw), **'No obedience in what is sinful ... obedience is only in what is right'** (Al-Misri and Keller, 1994). In simpler words, the husband should not seek to control every detail of his wife's life. If one should impose such restrictions, they themselves are causing sin. As the interviews progressed, many participants disclosed further information about their relationship with their husbands:

'My husband has been having affairs. So many girls have rung me up and told me. Once when I was pregnant with the third child, a girl rung me up and told me to leave him (crys) [...]. I asked him, before he kept saying no but now he says he is the man and he can do what he likes and I cant stop him (continues to cry) ... my life here is unbearable who do I tell I have no family here. I cannot tell my parents because they will just worry about me and wouldn't believe me anyway, I don't know what to do, why is it one rule for men and another for women' (Naila, 26 years old).

For participants who had suffered such abuse, this had become a 'norm' in their family homes and lives. They would never disclose to anyone within the family home or outside, due to 'saving face' (Jik-Joen 2004). For many of these women their children became the purpose of their lives. They were living their lives through their children and through fulfilling dreams such as educational opportunities and employment, as well as advising them to maintain their religious identity.

'Everything I could not do I will make sure my children do. I would encourage and support their decision in life; I would not impose my beliefs on them. They need to live their lives and mix with other children. They learn how to live and how to stand on their own feet. I let my girls have the decision if they wanted to go college. My younger daughter is at university now studying psychology, she wants to carry on, which is fine with me. Here in England it is different children all mix, I just tell my children do not do anything silly because I will be ashamed and people will say I let my children go free and did not teach them right way. My children all pray and go out with friends I never got to do that but it is different here' (Farhat, 46 years old).

'Um like I said my parents were strict what we wore how we talked walked everything mattered. Where as my kids do get all the freedom they want you see we use to do things behind our parents back like say we are working but you go out whereas I

hope my kids would and do tell me, we weren't allowed that freedom. I think with my parents that's just what they were parents there was nothing wrong with that but I would like to say I am a friend to my kids too' (Arifa, 37 years old).

Participants in this study felt that some cultural practices that had been encouraged by their parents were inappropriate within the British society. One such practice was the 'sin' of mixing with the opposite sexes.

'Men and women don't sit in the same room ... that is what my mother says it is wrong to sit in front of gahr (strangers) men no one but your husband brother son or fathers should see you' (Farhat, 46 years old).

The mixing of men and women is not forbidden in the Islamic culture as long as no sexual thoughts arise. According to the Shariah law 'interaction with the opposite sex in not forbidden. [...] as long as the intention is pure and all dealings are in line with the teachings of Islam' (Al-Misri and Keller 1994).

'I must confess yes some I do carry out myself like when my husbands friends come to the house I do either go out with the kids or go into another room probably out of respect and yeah it is probably something that I always did at my parents house too. My children do too, but times are changing, after all we are all equal humans, so why should one be above the other' (Neelam, 29 years old).

Summary

Historically, in Western culture women's role within the family has been to nurture, provide and care for her husband, children and the extended family. This role has changed dramatically as women have become more independent and seek full-time employment outside the home (Chakrapani and Kumar 1994). Within this study, many participants practised the historical values where the men provided and women naturally became the homemakers. Slowly but surely Muslim men are beginning to allow their women to work, although traditional beliefs sometimes take preference. Women spoke of how they wanted to adopt contemporary values of the Western society.

'I was not allowed to work, but I will encourage my children to go college and to work, you have to be independent' (Abeeda, 57 years old).

Cultural beliefs influenced every aspect of the participants' lives, and evidently provided a lens through which participants viewed their health, their life and themselves. Caring was a gender specific role. All participants were ascribed the role of caring for the elderly family members, whilst the men of the household sought paid work. According to Stuyft et al (1996) religious misinterpretations have sometimes supported the inferior status of Muslim women by providing them with limited access

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to the outer world. These beliefs are culturally engraved into the Muslim society, a belief that has been taught from childhood.

Hawthorne et al (2003) also states the status of women in the Asian community can cause problems when accessing services, as many are more concerned about the health of others, which was also evident in this chapter.

Family systems and roles have changed over time. Most of the interviews with participants were conducted with other female members present. In the household of the older participants there was definitely an observational difference, daughters and daughters-in-law all covered their heads with a scarf, however their children appeared to be wearing Western clothes. This suggests that certain cultural adaptations are becoming more common in the Muslim communities. Living in extended families was the norm, but some indicated that they desired the nuclear family concept. The Western view of the nuclear family as a married couple with 2.4 children is clearly a preference for many of the younger women in this study. However, this preference did not change the fundamental importance of 'Me my family and I'.

In the next chapter, I will consider the one fundamental aspect of the Muslim communities, 'Islam' their religion. Here I will explore the concept of religion as a referential framework, and as a way of life.

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Hawthorne et al (2003) also states the above view is a common one, but
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participants were conducted with other families and roles, and the research on
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Chapter 7: Findings

'My religion my identity'

Introduction

In the previous chapter the influence of culture and society on the life of participants was considered. Many lived their lives in line with religious teachings. The importance of 'Islam' on their life was clearly articulated in their narratives.

Within this chapter, 'Islam as a way of life' will be considered. All the women in this study assigned great importance to Islam. Their daily tasks, and their whole lives were based on their religious teachings, and teachings of significant others including, their husband, their parents, Peer Saab (spiritual leader), and religious leaders (Imams, Molvis).

Islam provided a protection for many participants away from the wider society. Recent terrorist attacks had become a part of their narratives. Many had undergone racial abuse, and noticed increased hatred towards their religion following the terrorists' activities. This forced many to turn to their religion as a way of protection and belonging together. Islam had therefore become even more entrenched as 'their identity'.

All participants referred to their religion and their religious books to maintain an Islamic life. Daily life was lived in accordance to their religious beliefs. To begin with, I will provide quotes that indicate what Islam meant to the participants in this study, and why many had begun to identify themselves through their religion. Their role as Muslim women is considered. This was usually perceived through the acts of elders in their families.

'Islam is a way of life'

'For me being Muslim is following what the prophets have told us, we haven't seen God but you believe someone up there is always looking over us. God is always with us, you cannot hide anything from God. All good and bad is from God. I pray and worship God every time. What ever I do, I do in accordance to what my religion asks of me' (Nazia, 54 years old).

Islam is based on the five pillars, which all Muslim women were aware of 'Iman, Namaz, Roza, Zakat and Hajj'. These are explained further below:

Chapter 1: Findings

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Islam is based on the five pillars, which all Muslim women were aware of. (Norman, Rose, Zakat and Hajj). These are explained further below.

- Iman: there is only one God (Allah) and Muhammed (saw) is his messenger.
- Namaz: the performance of daily prayers, which are carried out five times in a day. Prior to namaz a Muslim is instructed to carry out ablution (wadu), which is the washing and cleansing of body parts.
- Roza (fasting): fasting is carried out during the month of Ramadan. Muslims should not consume any food or fluids between sunrise and sunset.
- Zakath: donation of wealth is expected to be given to those in need.
- Hajj: pilgrimage to the holy city of Mecca, should be performed once during the lifetime of a Muslim (Penney 1995 pg 14, Khan 2003 pg 40).

The first four pillars are those that should be completed on a regular daily/yearly basis. Muslims are required to complete the Hajj (pilgrimage to Mecca) only once in their lifetime.

Participants' lives were based on religious teachings by significant others and following the way of life by the prophet Muhammad (saw). Terms such as 'peaceful', 'non-judgemental' and 'pure' were used to describe Islam:

'It is the way of life. Whatever I do, I do it with my religion in mind. It is very important to me. Um Muslim is being good to everyone and doing good not hurting people you do not hurt people and no one will hurt you (Farhat, 46 years old).

'Islam is a way of life, God teaches us how to live, do no harm and no one will harm you. I have strong belief in my God, and whatever he puts in my way I know he is testing me and with his help, I will always come through as a better person. The only thing he asks us to do is pray and worships him. All good and bad are from God but the good will always succeed' (Khalida, 42 years old).

Following any religious group means following certain guidelines. It provides a way of conforming and behaving, as stated by Nadia:

'Without culture there would be no religion, and without religion you would not be following the right cultural practices. Religion is, it's our faith what we believe in its what gets us through it's like the 10 commandments, um what Muslims have are the five pillars of Islam' (Nadia, 37 years old).

For participants born in the UK, there was a belief that religious teachings and practices had been forced upon them as children; religion was something that as children they did not understand:

- Imam: there is only one God (Allah) and Muhammad (saw) is his messenger.
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For participants born in the UK, there was a belief that religious teachings and practices had been forced upon them as children; religion was something that as children they did not understand:

'When I was younger we were forced to pray and go to the mosque. Every morning even weekend we had to pray it was then something you just had to do so you did. Without ever knowing why, you did not ask. But I advise my kids to pray they go mosque every evening, but I have to admit weekends I make them pray for one hour and then they do what they want. Although the difference is that I explain to my children why things are done and why they are the way they are' (Hajira, 21 years old).

'Like I said before I did not understand my religion, yeah I did pray and go to mosque but ...since my husband came into my life things changed for the better. Now I live, as a Muslim girl should, I pray and worship Allah ... I have full faith in my God and things are getting better. We are being tested in this life; you should never give up faith in hardship. My husband came into my life like an angel and look at me now. I realised only then what being a Muslim is, it is my life' (Roshin, 28 years old).

Maintaining religious practices with their offspring was as important if not more important than education in British schools. For the older participants in the study this was especially true. For those born in the UK, Islam became more important than it had done whilst they were growing up. Many had adopted Islamic culture in later life. One reason for this was related to the terrorist attacks, and the extent to which participants felt personally targeted. All participants stated that their religion was a peaceful religion and violence was not tolerated or encouraged.

'Islam is a peaceful religion ... just cause I wear a scarf doesn't make me a bad person, nowhere is Islam does it say you should hurt others who don't believe in Allah. People have got it wrong' (Aisha 28 years old)

'Like I said I live my life in accordance to Islam I don't do any harm to others and I don't think people should harm me just because I have a particular faith and wear a scarf that doesn't make me a bad person does it' (Aisha, 28 years old).

'The most important thing for a Muslim is their religion and that is for me too I would like to say that I live my life like a Muslim should I do not hurt others and I would not expect others to hurt me' (Salma, 26 years old).

It appeared through the narratives that many participants would emphasise and justify that Islam is a peaceful religion and that they themselves are Muslims. This was also visually evident, through their clothing, and the ornaments and religious books in their homes. It would appear that for the participants Islam had become 'key' to their identity:

'Um I think I would say my religion is very important to me, I am a Muslim and I am proud of it. No matter where I am, or who I am with, this is something that is going to be with me something that is always on my mind all the time no matter what I do. It is right' (Zarina, 39 years old).

'Islam is my identity'

Older participants born in either India or Pakistan and who had lived in the UK for over 20 years, identified themselves as 'British':

'Our parents homes are back home in India and Pakistan this is our home cause this is our society we are British and British Asian I mean I will always say I am British, yes I was born in India' (Saleema, 35 years old).

However, for those born in the UK identifying themselves as a Muslim was more common.

'Um I am a Muslim women living in England have two kids married and work ... My religion is my identity. Being Muslim is my life I am a Muslim and I am proud of it I don't I have anything to hide I am religious and I follow all my religious teachings so it is very important to me' (Aisha, 28 years old).

'Myself (pause) um Muslim Indian I think, I am British but I suppose no matter how much you want to fit in the first thing people see is your colour. I think it is harder for us who are born in the UK anyway, no matter how much we try and fit in, we will never be them. So why not say you are Muslims' (Khalsoom, 26 years old).

'To our people I say Pakistani, but to White people I say British Muslim. Well to our people they know, you wear a scarf you are a Muslim, but other people, as the White people do not know. They just think everyone brown is Muslim, well you and I know this is not true. There are so many religions in this world and so many brown people too. Therefore, I have to tell people who I am, and I am a Muslim' (Farhat, 46 years old).

It seems that at least some of this emphasis is a reaction to the negative perceptions that the wider British society may hold about the Muslim communities. The 9/11 and 7/7 terror attacks have had a negative impact on the social identities and the well-being of Muslims in many Western nations (Borger, 2006, 2007). Some participants in this study stated that, after the attacks, they felt scared to leave their homes:

'Since all this happened the attacks, I am scared of leaving my house. People just presume you wear a scarf and you are automatically a terrorist' (Habiba, 50 years old).

'I think now younger British born Muslims like I am more aware of our religion and what it teaches us. I think since all the media attention you want to know more and more, I mean for instance it could be any religion that was targeted and I suppose it is just human nature to want to know why and questions things. Although I believe we are being targeted for the wrong reasons the media has always had a negative influence on people and that is what is happening again' (Noreen, 26 years old).

'You wear a scarf and people think you are a terrorist, they don't know but Islam is the most peaceful religion in the world. Yes you get some naughty people. Like I

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always say because of one person everyone else is thought to be the same. It's wrong' (Khalida, 42 years old).

All the participants in this study felt very strongly about being targeted due to their religion. Many stated that Islam was the most peaceful religion, and just because someone says they are a Muslim or utters the word 'Allah-hu-akbar' [Allah the greatest/Almighty], does not indicate that they are Muslims or even terrorists. True Muslims do not cause others any harm or hurt. Participants born in the UK felt the media was the cause of their negative image, and that it showed negativity towards their faith.

'People say everyone is an individual and should be treated as so, so why am I being targeted because I wear a scarf. I am not a terrorist, yes I am a Muslim. God, when the IRA stuff happened, were they abused like we are now. Not everyone Irish is a terrorist, so not ever Muslim is [...] Media has a big role to play in all this especially if you are a Muslim (pause) I think we are negatively seen in the media how do you know that these people are really Muslims. Islam is a very peaceful religion and it does not state anywhere that people who are not Muslims should be killed. That is what the media states it is wrong I would never call anyone else's religion so I don't think people have the right to call mine do you' (Aisha, 28 years old).

The current media attention was seen as a way of targeting Islam and Muslims. However a small number of participants saw this current attention as a positive influence, a way of people wanting to know their religion, and learning the Islamic way of life:

'Of course Islam is important worldwide too, people are wanting to know more about Islam even if they have negatives thoughts about our religion at least like that people understand there is no difference between their religion or ours, except for who we worship, and all these attacks that are happening is not what Islam says. So I think people are learning the true Islam, the peaceful Islam' (Khalida, 42 years old).

'Now it's more important because now people are realising they are reading more into it and finding out what Islam is really about. Because of all the media attention people are wanting to know why what when kind of thing ... I think it is even more important in Britain because people don't understand as well as they would in Pakistan so its more important that we follow it the right way' (Mariam, 34 years old).

Many felt that the current media attention was not only related to the terror attack, but also to their attire and male domination that the British society attributes to the Muslim communities. Many believed that only recently have those Muslims born in the UK changed from wearing Western clothing to the traditional Islamic outfit, again using clothing to form part of their identity:

'Today Islam is the talk of everywhere people are stating they are Muslims before British now I think people are trying to make a statement. It was rare to see a young Muslim girl or guy dressed in the traditional "Muslim" clothing, but now you tend to see loads. If this is not making a statement I don't know what is, people are not conforming to Western ways anymore ... I mean like wearing jeans caps you know they want to learn about their religion although I believe many have taken it too far. People are scared of Muslims but not every person is the same think about it ... Islam has always been in the centre of the media for centuries but people do not stop being Muslim or even converting to Islam' (Nadia, 37 years old).

All those interviewed in this study wore the traditional Asian outfit of *Salwaar Kameez*. Out of the 41 participants, 38 wore a scarf on their heads, one wore the full hijab covering the face, and three wore Asian clothing at home.

'I used to change from my Western clothes into Asian when I use to live with my dad. However, since I got married I sometimes just stay in my jeans. I suppose though Asian clothes are so much more comfortable. Does it matter what you wear anyway, it does not make me less Muslim or them more Muslim' (Ameena, 27 years old).

According to Shahid (n.d.) 'a Muslim woman's dress itself, is her submission to God and her acceptance of Islam as her way of life'. The traditional outfit for a Muslim woman is the Hijab, which is a long outfit, covering from head to toe, and loose fitting. Three different views emerged in relation to wearing the traditional outfit and these will be discussed as follows.

'No need to cover face'

Participants who wore the scarf daily and those who wore it on certain occasions felt that covering the full face was not a religious requirement. They believed that covering the head was more important from a religious perspective.

'You decide what you want to wear I mean if I decided not to wear anything, then that would be my decision. Yes, my religion does ask women to cover their bodies not their faces. However, it is culture that has stated women should cover their faces not religion people need to make a difference and learn that they are two different things' (Aisha, 28 years old).

'One of my neighbours who is White said to me um I am going down the street and people are saying hello I am saying hello back but I have not idea who they are but they can see me. I can't see them and she asked me being a White lady a Christian the wearing of the veil wasn't that supposed to be for men but I'm a woman and why are they covering from me. So isn't that there a little bit of culture mixing in with religion there, and they are neighbours. I mean how are they going to get on I mean the neighbours I just think it is just a fashion statement' (Rashida, 34 years old).

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According to Ghafar (n.d.), a Muslim woman's dress itself, is her submission to God and her acceptance of Islam as her way of life. The traditional outfit for a Muslim woman is the hijab, which is a long outfit, covering their head to toe, and loose fitting. Three different views emerged in relation to wearing the traditional outfit and these will be discussed as follows.

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Statement of being 'Muslim'

For some participants their clothes, i.e. wearing the hijab or the scarf, had become a statement. This statement was related to their religion, as the wearing of the scarf or the hijab is seen as Muslim attire for the women.

'I do wear a scarf and I have since a child but I also believe the way you dress makes a statement in it self ... that I am a Muslim' (Aisha, 28 years old).

'Yeah to a certain extent yes it does, the way you dress you make a statement, and to me my clothes are my identity I am a Muslim' (Hajira, 21 years old).

'I started wearing the hijab, because that tells others, yes I am a Muslim. If they have a problem with that then hey that's their problem, not mine. I believe it does matter how you present yourself I mean if you dress just say for example in the hijab you are judged straight away as a terrorist. If you dress in a suit or something that states you are a professional then you are treated with respect but does that make you less Muslim no' (Roshin, 28 years old).

Choice of clothing:

Some participants felt that clothing was a personal matter, what people wear was their decision, whether that was the hijab, the scarf or Western clothing.

'Well I personally reckon pointing at women in hijab is saying (pause) going out on the street and saying I don't think anybody should be wearing caps I think its up to the individual what they wear and when they want to wear it. Yeah it can be a communication barrier with some people but if that is what they want to wear then they should its just individual choice' (Zarina, 39 years old).

Participants stated such views arise only when there is clear difference between the British culture and the Muslim culture, and is related to a clear lack of knowledge.

'People see a Muslim lady with a scarf, and what do they think. Oh she is suppressed, she has no life. Why is that? I work like my husband; we both look after the kids and the house. So I am sorry but people should not comment on something they know nothing about' (Aisha, 28 years old).

'I do get the looks where men look at you and think oh her husband must have forced her to wear this. People are narrow minded that is all I can say ... come on you must have heard Muslim women are suppressed, my ass you wear eat drink sleep what you like. Who are these people to judge us? I wouldn't go around saying oh why do these people walk around with nothing on, because that is what they do' (Roshin, 28 years old).

Due to such issues, many of the participants had experienced racism, which became part of their narratives. Many felt they were being targeted as a religious group, and that this inevitably caused many young British born Muslims to become radical (Mail online 2007):

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For some participants their clothes, i.e. wearing the hijab or the scarf, had become a

statement of being 'Muslim'.

'I mean people do not see you first they see your skin colour there is so much racism in this country it is unbelievable. It makes it so hard to live here' (Hajira, 21 years old).

'I have heard people say things like Paki and go back to your own country and things like that its not nice ... because I am probably different. Like you wear jeans and things I do not I do not think I would be comfortable wearing them. I try to fit in but it is hard I am not from here; my husband has said it will take time but I do not give up' (Zorah, 52 years old).

There was clearly a lot of anger evident in the narratives of the participants. This related to the negativity that surrounds them, being Muslim and living in a non-Islamic state.

Religious practices were none the less continued as many felt these were testing times, and those who survive and do not retaliate are 'true Muslims'. Many regularly referred to the Quran, the Hadith and the teachings of their parents and scholars of Islam, as a way of justifying why their behaviour was as it was.

'Religion as a referential framework'

As note above, participants in this study stated they lived their lives in accordance to their religious teachings; thereby describing Islam as a way of life. According to Shahid (n.d.), the role of a Muslim woman is unique and has been prescribed in Islam. Her role in life and responsibility to God, her husband, her children, other family members, her community, and society, as well as to herself have all been highlighted in the Holy Quran.

Participants described their role in Islam, which articulated two different perspectives; equality *'the same to what a Muslim man's would be (laughs) to um carry out your prayers believe in God pray and always do well'* (Noreen, 26 years old) and care for others. These two tenets are listed within the Shar'iah law, the Hadith, and the religious books written for the Muslim women.

These two codes of belief will be discussed further, as many participants stated their role as Muslim women was based on these.

Equality

All participants stated there were no difference in their role and the role of their husbands in regards to their religion. British born participants agreed with this, however they added that their parents sometimes imposed culturally driven views on them:

'Allah has made both man and woman, he did not give one higher status than the other. There are some roles that men can do and some women, but I would say there is no difference in the eyes of Allah' (Sofia, 37 years old).

'I believe the same as a man, although I think my mum would say differently ... well according to my mum a Muslim woman should stay home look after her husband and kids and obey every command he makes. I think a woman in Islam and I'm sure it is stated that has equal rights to a man it's like a partnership not I'm his slave or vice versa' (Nadia, 37 years old).

These participants had a strong sense of equality between them and their partners. However, other participants, felt more uncertain about equality of roles:

'Well (pause) in my eyes it should be not different to a man's role um but obviously other people have a different views. Society tends to see women as a more passive type, you know sitting in the home looking after kids things like that getting outside the house and working is not really what is seen for a women. Its socially not acceptable like if I went out to do a job I don't know just say a builder (laughs) its not something that is socially accepted not something a women should do' (Hajira, 21 years old).

For those who migrated to the UK, the importance of their partners was noted through their narratives.

'Being a Muslim girl you have your limits, you know when not to step over the mark. We have been told to respect our husbands and whatever they say to listen to' (Sadiah, 27 years old).

Care for others

Participants also felt that as women their role was to care for others, which included their immediate and extended family. This was similar among those who were born in the South Asian countries and those born in the UK.

'A role as a women well (laughs) have kids loads of them look after the husbands family cook and clean and pray we really do have busy lives don't you think' (Khalida, 42 years old).

'Like as a woman I have been taught to look after others before myself, these people would include my husband and my children. If I have a health problem I would have

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Like as a woman I have been taught to look after others before myself, these people would include my husband and my children. If I have a health problem I would have

to not only consider what it is doing to me but what would happen to them lot too' (Tanzeela, 37 years old).

'To work in the house have children look after the husband and his family (laugh) I have never worked not in India or here women should work I think cause you need to feed yourself but men interfere and start thinking suspicious thinks (pause) so you are better off staying at home' (Fatima, 70 years old).

Caring for others usually meant their partners and their offspring. Only some of the women interviewed lived in households consisting of their in-laws. For British born participants, the family usually consisted of their own children and the married couple, with extended family members living nearby.

Participants were asked about where views of equality/inequality, respect and care had emerged from. In response, they would either refer to their religious books, or ask the elders of the family.

'In my eyes yes even from what I have read from the teachings of Islam a woman and man should be treated equally but you know things are said and done differently' (Hajira, 21 years old).

Some women stated the higher status of men in Islam was a cultural trait, which related to men being cherished within Asian communities, as they would bring wealth and prosperity to their family home.

'The men are always thought as higher than women um the women are I don't believe this but like other people see them as second class citizens but I don't think that is really religion but culture they way you have been brought up in' (Saleema, 35 years old).

The way a Muslim woman should live her life is indicated in the Quran. In these texts there is a full chapter dedicated to Muslim women. However, the Quran is written in Arabic, which many of the participants were unable to understand. The reading of the Quran is taught from a very young age, but the meaning of what is being read is very rarely discussed. Today the Quran has been translated into many different languages, and for those who are unable to read for themselves, there are now audio recordings.

Prior to the availability of translated texts, many Muslim families would consult their Scholars, known as Molvi Saab, Imam's or Peer Saab's, for advice on living life as a devout Muslim. Although the guidance by these Imams has proved beneficial to many older Muslim communities, reference to the Quran has been lacking.

Consequently, some participants in the study continued to regard their parental teachings as Islamic rather than culturally orientated. A few of the participants stated they would only refer to their religious texts to understand the true nature and meaning of life.

'It is written'

The Quran and the Hadith are the two main religious texts of Islam. Many participants in this study believed that the teachings of their parents, Imams, Molvi Saabs and Peer Saab's, were all religiously based, as opposed to being culturally motivated.

The theme 'it is written' relates the narratives of the participants regarding the status of women in an Islamic society. The belief that men are regarded as superior than them, women looking after the family home, the upbringing of their children, and so on, were all believed to be religiously significant.

'Well yeah it is important because my mum said it is, and that is enough for me. I live the way I am supposing to because this is the way our parents grew up too, respect and obey your husband and elders. The have bought us up the right way, the Islamic way, you see your elders doing things in a certain way and you follow. I have not read myself probably because I cannot read Arabic and my Urdu is not too good either [...] no I have not read myself but mum has told us about it and so has my husband, and that is the way I live' (Aisha, 28 years old).

'Well, I cannot read or write but this is what Islam says [...] from the Quran and Hadith, have you never read it [...] my parents told me and my husband too. He can read Urdu so I have asked him about it' (Nazia, 54 years old).

Scholars of Islam, the Imams and the Molvi Saab are thought of highly by participants. Many participants felt that these people were very knowledgeable about Islam and its rules and would consult with them regarding advice and ceremonies that are held in their communities. However, as women, the participants did not have direct contact with such people. The women considered that communication with men to whom they are not directly related was religiously forbidden.

'For girls to sit in front of men is wrong. You can in front of your father or brothers [...] he [husband] wouldn't want me to have male friends either, you see boys that have been born in England, they have seen how their sisters are bought up, not going college staying at home, so why should they be different to us' (Naila, 26 years old).

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It is worth noting that many participants especially the older women would not allow their daughters or daughters-in-law to work outside the family home due to this belief. However, reference to the Islamic law, reveals that this is not religiously correct. Al-Misri and Keller (1994) state that interaction with the opposite sex is not forbidden, as long as the intention is pure and all dealings are in line with the teachings of Islam.

Participants born in the UK would gain religious knowledge taught through their Imams and Molvi Saab at mosque. This is the only time a girl would ever enter the mosque. Once the girl has reached puberty, she is forbidden to enter the mosque, and practices such as no contact with men and modesty are imposed on her. Molvis and Imams also enforce these practices. Not every Muslim regards such acts as religiously orientated rather than cultural practices and the reason for this is based on the teachings of different scholars and religious leaders. As stated above, though Islam is regarded as one religion, there are different interpretations of the Quran and the Hadith. Sunni Muslims and Shia Muslims do in fact share the most fundamental Islamic beliefs (refer to pages 69-70). The difference between the two initially stemmed from political differences, which then gave rise to differences in religious and cultural practices:

'I went to a mosque here it was strict. I would say Islam is one religion but there are subsets meaning we have Sunni, Wahaib, Shia and many more. So bringing all these together has caused people to follow more culture than religion when we use to come home from mosque my dad use to teach us our way which is Sunni' (Arifa, 37 years old).

'Well they [Imams and Molvis] teach you different ways of Islam but there isn't different ways cause there is only one way but they put their culture and mix it in with Islam and confuse you for example this is the type of dress you should wear when is Islam this is not the case' (Noreen, 26 years old).

For many participants religious and cultural teachings became entangled. The only way such commonly held beliefs could be changed was through reading the original texts themselves instead of asking others. Whilst gaining knowledge from the elders was a common practice that many continued, reading for themselves was highly recommended. For those who had poor literacy skills, the only source of knowledge came through their elders.

'You don't ask others; you can read for yourself, these people change things as they go along. I just read for my self now, and now these books are all in English too, which makes it so much easier for people like you and me. There is only one way, but these people have all made up their own practices and things' (Ameena, 27 years old)).

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'I believe it is very important religion is very important it teaches us what we should be doing but it is annoying when either culture or society try and change that which I believe they do (Noreen, 26 years old).

The different interpretations of the Quran and the Hadith have caused many Muslims to quarrel among themselves. Throughout history, the Sunni and the Shia sects have fought on the grounds of Islam. There is only one Islam and people should regard the Quran as the holy book referring to it for guidance and support. Elderly family members who dictate practices cause many to encounter barriers to opportunities for women such as seeking employment and education.

Another such area where religion restricts women is health care, where modesty and examination by male health care professionals has been regarded as religiously incorrect. Chapter nine discusses this phenomenon through the words of the women participating in this study. The chapter also illustrates the impact that this can have on their lives and their health.

Summary

For all Muslims the Quran the Hadith and the teachings of their parents and the Imams were all as important as each other. For participants to give importance to one was not an option. They believed that they were taught specific 'practices' for a reason and, for many, it was assumed these would automatically be passed on their children. Although the quotes above also illustrate that many of the participants felt comfortable and happy to allow their children to behave in a more Western way, which included education and employment.

Islamic books are vast. As already noted, the Quran is the only true source, followed by the Hadith, which are the teachings of the prophet Muhammad (saw). The Quran is regarded as the book of guidance, which contains the basic principles of Islam. Generally, the Quran covers matters of belief, the duties that are compulsory and code of conduct, which Muslims must follow. Participants all stated they lived their life in accordance to Islam. Most of the participants wore the headscarf, which was an emblem of their religion for these women. Islam was their core identity.

Due to the terrorist attacks, many of the participants felt an increasing sense of suspicion from non-Muslim neighbours and the wider society. Consequently, many adapted or returned to their religious practices to show a form of 'belonging' to a

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group. Many authors have reflected upon the effects of the terror attacks on the Muslim communities (Fekete 2004, Hall 2004). Although this study was specific to the influence of religion and culture on South Asian Muslim women suffering from urinary symptoms, the terror attacks became a part of many of the participants' narratives. The events of 9/11 and 7/7 had a negative effect on the social life and health of some Muslim women in this study. Although the older women did not appear to be affected by the attacks, the younger participants felt targeted personally and decided to turn to their religion for support.

It was also seen in this chapter that participants noticed media attention towards Muslims, whether that was the terrorist attacks, male dominance in their community or women labelled as being suppressed. As a consequence, participants felt the need to actively defend or reject such practices. Some felt that the attention illustrated a lack of knowledge within the Western world about the subtleties of their communities and societies. Some stated that British society had a narrow vision of their communities, which did not reflect reality. All participants stated that Islam supported that both men and women as equal and there was no superiority (Al-Baqara, 2:228, Quran; Abu-Lughod, 2004). However, paradoxically, practices that restricted the movements of women were noted, relating to employment, education and the segregation of the sexes (Al-Misri and Keller, 1994 pg 510-514; Barlas 2002, pg139-149).

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Chapter 8: Findings

'It's the norm'

Introduction

The previous chapter drew attention to the importance of religion (Islam) as an influential factor on the lives of the participants. The impact of religion is immense and can affect every part of a believer's life. Religion for the women in this study is a fundamental part of their lives. Adapting to religious or culturally driven religious views and practices was evident through their narratives and their accounts of their environments.

This chapter will focus on participants' views on and experiences of urinary incontinence. As noted in chapter two section I, urinary incontinence is not a disease in itself, but a condition with many underlying causes (Abrams, 2006). People who suffer from the symptoms of urinary incontinence generally regard the symptoms as a normal part of ageing and/or naturally caused by childbirth (Norton 1986; Bump 1993; Herzog et al 1994; Bump and Norton, 1998). These beliefs are echoed in the data of this study, under a theme titled 'its the norm'. Two sub-themes emerged from the data. The first is titled, 'is it the norm?'; here participants began questioning whether UI was normal. This leads to the final sub-theme 'it is NOT the norm', which only became clear when religious obligations were linked to UI.

'It's the norm'

The theme 'it's the norm' is connected closely to the duration participants suffered from UI. The longer the period, the more likely participants felt it was a norm:

'It's been happening for a long time now [...] I thought it was normal' (Khalida).

The belief that UI was normal was consistent among those participants who had not sought help and those who had sought help. Some participants referred to UI as a normal part of ageing and a natural consequence of childbirth:

'Yes it is when you have had kids and the more you have the worse it gets. You see it's not up to the woman how many kids she has, the man decides that but I have the

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'Yes it is when you have had kids and the more you have the worse it gets. You see it's not up to the woman how many kids she has, the man decides that but I have the

coil fitted now so its not a problem but I had 6 kids and one died. So it's normal for me' (Fozia, 26 years old).

'Having so many children is the first thing plus I am old now and it does happen cause everything starts hanging not like when you are your age everything is fine but when you have kids you will understand' (Sobia, 58 years old).

On average the women in this study had four parities, with a range of 0 to 9 parities. They reported that, within their culture, the higher number of parities they had the more value this brought, as their children would take care of them when they reach old age. For them this was the 'norm' of their Asian communities.

However, some participants felt the cause of their UI was not related to childbirth:

'She [physiotherapist] said having children, I don't think this is right. I have only five children, I know people who have had 10 or 11 children, they don't have this problem' (Ghazala, 76 years old).

For those participants, who had caesarean sections or no children, believing UI was related to childbirth was illogical. Participants stated that professionals would inform them that leaking urine was associated with a high number of birth rates, without even gaining their history:

'Um well X [physiotherapist] told me giving birth, but with all my children I had operation not normal birth way. So I don't think for me that is why. Maybe the operation [c-section] caused me to become like this plus I also get a lot of infection too' (Nazia, 54 years old).

Vaginal childbirth has been considered as one of the many factors contributing to the development of urinary incontinence. Vaginal childbirth does not just cause injury to the pelvic floor muscles but also to innervations, which can eventually lead to urinary incontinence (Snooks et al 1984, Swash et al 1985, Snooks et al 1990). Previous literature has therefore shown a positive link between urinary incontinence and childbirth (Hagstad and Janson 1986, Diokno et al 1990). Foldspang et al (1999) reported that during pregnancy 53.9% of women reported urinary symptoms; and that, following childbirth, 49.7% will remain incontinent of urine. However, this persuasive evidence does not excuse a lack of careful history taking, which might reveal a different history than expected in women presenting with this condition.

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them that looking urine was associated with a high number of birth rates, without related to childbirth was illogical. Participants stated that professionals would inform for those participants who had caesarean sections or no children, believing UI was even gaining their history.

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coil filled now so its not a problem but I had 6 kids and one died. So it's normal for me' (Fozia, 58 years old).

'I tend to cough a lot because I have asthma, and that is when I tend to leak more [...]' (Arifa, 37 years old).

Through the belief of childbirth or other medical conditions, living with UI for a number of years became the norm it had become a part of their daily activities. Social activities, employment, home life were all affected. However, many participants felt they could cope with leaking urine if they stayed at home, including those women who had sought help and those who had not.

For those that worked outside the family home leaking urine in inappropriate places such as the work environment could be more devastating. However, many of these women had adapted self-management strategies to cope or conceal their problem. Commonly the women in this study utilised 'tena' pads' which had become as normal as brushing their teeth each morning.

'I wear pads every morning without fail now. You can guarantee if one day I did not wear a pad that would be it, I would totally leak everywhere. Its something that plays on my mind each time, especially when I am at work. I always carry some in my handbag' (Zorah, 52 years old).

'That is the problem you are not in your own environment. I mean can you imagine if I had a mishap like that at work god, it would be so embarrassing (pause). I've got to admit I always do wear pads at work all the time. My problem isn't so bad like others I know but it human nature to laugh at others, I know I would if someone had a wet patch' (Arifa, 37 years old).

Only one participant felt she had to leave work due to urinary incontinence:

'I worked when I got here [arrival into the UK], in a Bakery, but had to leave [...] because of this problem' (Zeenat, 52 year old, Pakistan).

Participants became hyper-aware of their surroundings, and, specifically, the location of the toilets. For them this was a 'normal' management strategy that had enabled them to cope with their UI:

'Well yeah it does effect me, because environment in this case would mean the finding of toilets and things so if you needed to go toilet and couldn't find one then you would leak. Like when you are out with friends, you scan the place to see if you can locate the toilets, but I always carry pads with me, you never know when you might need them' (Aisha 28 years old).

Even though many of the participants repeatedly mentioned issues relating to leaking urine, they controlled UI. Self-management strategies helped these women to conceal their problem, and prevent leakage.

'If I need to go anywhere I drink less. Before I pray I drink less and go toilet before doing wadu [abulation]. I don't really go out a lot but when I go to bed I have to get up regularly to go to the toilet and sometimes urine has come out, so I don't sleep much now it's a habit. If I am up early I pray you should remember god all the time (pause) you see this is a way of God wanting me to pray so sometimes I think it is good, sometimes its not good because I smell sometimes and I have to all the time make wadu' (Fatima, 70 years old).

A common preventative or self-management method that many carried out was restricting the fluid intake, especially where travel was necessary.

'I don't even drink water a much just in case I leak [...] I have a lot of family living in Birmingham and I go to see them a lot, but I make sure I go to the toilet before we leave the house. We have to stop at the service station and I go first thing when we get there. I have sometimes worn the big pads that my mother in law has. You know she also has this problem, they are big so I take them' (Sofia, 37 years old).

'I have to go to the toilet ever couple of hours, whether I want to or not. Because I do not want to leak anywhere, if I do not make it to the toilet in time I have wet myself. This is my life now; I just sit in the house' (Shahista, 54 years old).

'Is it a norm?'

On reflection, despite normalising strategies, participants generally agreed that UI did affect them and was a concern especially when in the company of others:

'You have it on your mind you just cant be yourself [...] I think if they found out I would probably die' (Aisha, 28 years old).

Due to such concerns, many women had isolated themselves from socialising including family events, for fear of leakage and odour.

'I feel so lonely in the house especially after my husband died. Don't get me wrong I have all my family around me, but they have their own families. They come sometimes in the evenings after work [...] I have changed a lot I use to be an out going person. Loads of people use to come to our house and things, but it has all changed, I cannot do things as I use to. I just feel maybe they may smell it, it's not nice' (Fatima, 70 years old).

Even though many of the participants repeatedly mentioned issues relating to leaking urine, they controlled UI. Self-management strategies helped these women to conceal their problem and prevent leakage.

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These feelings have been highlighted in previous research. For example, Thomas et al (1980) found incontinent individuals became socially isolated and embarrassed, and concealed their leakage or withdrew from society altogether (Yarnell et al 1981). None of the participants stated in exact words that UI made them feel depressed or they had felt upset by becoming isolated in their own homes due to UI. However, this may be related to the social stigma related to depression in Asian communities (Raguram et al 1996; Conrad 2005). There is growing evidence showing an association between depression and urinary incontinence (Heidrich and Wells, 2004). This is important because it reveals that many women with incontinence may have forms of depression that are often undiagnosed or untreated (Zorn et al 1999; Vigod and Stewart 2006). Forms of depression differ significantly according to incontinence severity and type, with a higher prevalence of major depressive symptoms in respondents with moderate and severe incontinence (Melville et al 2005).

Possible contributors to depression in this study included feeling lonely, no social life, and few friends, which were reported by 12% (n= 5) of the study sample:

'My problem has become so bad I don't go out anywhere, if I do I have to make sure I know where the toilets are (upset, starts crying)...If I have to go anywhere I use the toilet before I leave and make sure I know where the toilets are [...] You know I do not go to family gatherings (upset). No because of this, you know I don't even drink water a much just in case I leak...' (Shahista, 54 years old).

'I am trapped in this house I can't go anyway because of my illnesses, I don't see anyone. I just sit here and think and think (continues to cry). Would you think I was 46 tomorrow? I use to be so independent and confident, I even won awards in London for the work as security, and I even escorted stars. Now I have no confidence, if you tell me to go and talk to my neighbours I have to think ten times before doing anything. I am so lost' (Hameeda, 46 years old).

One participant stated leaking urine restricted her having a sexual relationship with her husband. This was distressing for her and her husband.

'I don't even have a relationship with my husband you know. I know he gets upset ... no because all channels are dry now, and it hurts so much ... sometimes it has come out when we (pause)' (Shahista, 54 years old, Pakistan).

As the interviews progressed it became apparent that participants started questioning themselves regarding UI. Participants who had not sought help for their UI were amazed that UI was a health issue, and help was available.

'I didn't think it was a problem [...] I only realised when I saw you at the English classes and thought I have this problem didn't tell anyone else before this, people would laugh. It is like a big woman having baby problems' (Rukhsana, 39 years old).

'I didn't realise incontinence can be made better, I just use to think oh I am getting old now that is why this is happening. It's embarrassing isn't it is like a baby, people will laugh at you but I will go to the doctors. I will be shy but it is better because I do pass water sometimes and it can be bad like when I stand up quick and things um...' (Zeenat, 52 years old).

Similar beliefs were also noted in participants who had sought help. Even after seeking health care, a sense of disbelief remained.

'I did not realise it was such a problem, I just thought oh well I am getting old now, what can anyone do for me. My doctor had told me I get a lot of infection down here [UTI] so that is what I believe, and that is why he told me to go to the big doctors in the hospital [...] they will take out the infection' (Farhat, 46 years old).

For some women who had sought help, their knowledge regarding UI had improved and some even felt confident in informing others about the help available.

'My friend also has the same problem, I told her what I did and she is going to the doctors, her problem is worse than mine. She had this problem at work one day. It was not nice, because we work in the Bakery, and everything has to be clean. When it happened to me the first time my daughter got me small pads and I told my friend to go to Tesco, that is where I get them from' (Khalida, 42 years old).

'I know more about incontinence now than I ever did. I am glad I told my doctor. Everyone has been a good help and things people have explained things to me' (Farhat, 46 years old).

Participants felt the media played a big role in providing people with knowledge about health issues. It is worth noting that many of the women in this study had low literacy skills, which also covered their own native languages. All participants were orally competent in their own native languages. For the participants media consisted of the Asian Sky Channels¹⁸, Urdu is the language used by most of these channels, as well as Punjabi, Gujarati, Hindi, Bengali.

Participants felt Asian channels or channels in general do not address the issue of UI.

'I haven't seen anything about this on TV (Naila, 26 years old).

¹⁸ The Asian channels available on subscription include Star News, Zee TV, Sony, B4U, Star Plus, Max, Alpha Punjabi, ARY digital, and also the Islamic channels, Abu Dhabi, MTA Muslim TV, Prime TV, South 4U, Venus TV, Islam channel, GEO TV, Noor TV, Peace TV.

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They did note that general health promotion such as smoking, heart disease and healthy living were all concepts that had been well covered:

'I have our [Asian] channels. On there they are showing things about smoking and heart attack. I have been telling my husband to stop smoking but he won't listen' (Farhat, 46 years old).

'I have not heard anything on television. I have Zee TV not seen anything on that. If I had I would have done something about it before, its just people have told me it's an infection and so did the Peer Saab so I didn't do anything' (Ghazala, 76 years old).

Participants felt the lack of their knowledge and the lack of public awareness caused a barrier to seeking health care.

'Well it's pathetic because people tell you about cancer but they don't tell you about this do they. ... I mean like in school or college you learn things, obviously that's how you get to know things no one tells you that you may sometime in life suffer from incontinence or what to do to prevent it happening. ... I mean you are aware smoking gives you lung cancer so you try not to smoke or whatever but how do you prevent incontinence happening (pause) no answer is there. ... Incontinence is not even talked about I mean you don't hear it on telly do you that someone a famous person has incontinence you just hear that they might have cancer or been in a road accident things like that. I mean the media influences a lot of people but there is no knowledge or awareness about incontinence I think it needs to be promoted more especially in the Asian society and older women' (Aisha, 28 years old).

Due to the lack of media coverage and the lack of discussion regarding UI and the interview itself, many participants began to question whether UI was normal. This was probably also my influence, my dress code as a staff nurse and the information provided had maybe led them to begin questioning this belief. Beyond these possible influences, participants related UI to other influencing factors that will be discussed further below.

'It is NOT the norm'

As noted above, for participants who had not sought help the general concept of UI was related to factors such as childbirth, something that every woman has to go through and old age. For those who had sought help, leaking urine had become visibly apparent to those close to them. Initially in the interviews, none of the forty-one participants related UI to religious obligations.

Participants were then asked about the impact of leaking urine on performing prayers. At this point, some participants felt they had committed a 'grave sin', by

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rushing prayers, leaking whilst under ablution or, indeed, that they had not prayed for a number of years due to UI:

'I have in the past yeah rushed prayers (Noreen, 26 years old).

Strategies were developed not to leak urine whilst praying, which consisted of toileting, squeezing pelvic floor muscles whilst praying and drinking less:

'No I have never leaked but I have had to squeeze myself cause I need to go toilet I tend to pray quickly (pause) sometimes it has happened so I have to do wadu again' (Habiba, 50 years old).

'Before I usually pray, I go to the toilet just incase I want to go when I start praying. At least this way I can give God my full attention. As a Muslim you need to be clean all the time, if I leak urine, how can I pray, you need to be clean to pray [...].

Arifa stopped at this point and realised that she was not paying full attention whilst praying as she would rush her prayers to prevent a leakage:

'... I am so ashamed of what I am saying ... if I have rushed prayers then ... I never looked at it in that way, I just felt like I was being punished. You see when things go wrong it means we have done something bad' (Arifa, 37 years old).

Participants further stated the inability to perform prayers, due to feeling dirty and leaking all the time, or worrying if they leak urine, made them feel worthless, and a sense of punishment by God was voiced.

'Like I said I am unable to pray and things which does affect me I feel like I am being punished for something ... I feel I cant pray or anything because of this problem. Its horrible because for us child we have to be clean for praying namaz leaking urine is unclean especially when you are praying ... just dirty and embarrassed lets not talk about that now, I don't want to ... no no child I just feel really dirty and helpless. No one can help me or don't want to I don't know, just leave everything to God now' (Nazia, 54 years old).

For participants who had sought help, the issue of leaking urine whilst praying became the turning point, from thinking UI was the norm to seeing it as not a norm.

'Very embarrassed, I felt dirty and ashamed of myself. It's not right, we have to do wadu before we pray if you leak urine, you are unclean and have to do wadu again. I have cried about it but what is the point crying. That was when I thought I will have to do something about it (Khalida, 42 years old).

Once the concept of leaking urine whilst praying was explored all the participants became aware that UI was not the 'norm' and felt 'they had themselves made it the norm'.

At this response I asked one participant how she viewed UI:

'It's not normal so it must be an illness, you only get medication for illnesses, I just didn't realise it was a problem, for me it was normal ... I was wrong' (Shagufta, 54 years old).

'Before never thought anything about it but now it makes me feel upset in the sense that I didn't think it would be such a problem but if I rush prayers than yeah it is [...] I didn't think it was a problem not until you asked about praying and if incontinence has interfered with it. Well yes, as I said it has because I have rushed prayers and not concentrated which is wrong when you pray to Allah. All your attention should be on praying not on other things. If Islam is important to every Muslim so is devoting your full attention to god' (Arifa, 37 years old).

Summary

It can be seen from the above discussion how participants in this study started with the belief that urinary incontinence was the norm, and moved to the view that it is not the norm. This change in perception appeared to be linked to a realisation of the impact of leaking urine during the performance of religious obligations. Some viewed leaking urine as a sinful act that could only be remedied by medical attention, especially if UI came between them and their God. For those women who had sought help then, religious obligations became the factor that encouraged them to seek help.

Urinary incontinence can have a devastating affect on the individual's quality of life (Abrams 1995). This can be seen in the above quotes taken from the participants' tense narratives. However, this appeared to be tolerated until the symptoms had an effect on religious observance, usually making the condition worse.

Leaking urine isolated many of these participants. Some stated that they felt low in themselves due to the restriction placed on them by UI. However they did not term this as depression, as this is a concept which is poorly understood within Asian

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communities. In some cases, participants related isolation to other kinds of ill health. It was only on further probing that some reported fear of smell, and of leaking in front of others, as factors linked to isolation. These accounts also included elements which might be termed depression in Western biomedical terms.

The next chapter will explore the theme 'hush hush', which relates to the sensitive nature of the subject area. Urinary incontinence or leaking urine in inappropriate places is rarely mentioned outside medical or nursing consultations. It is not a topic to discuss with friends 'over a cup of tea', nor is it the 'norm' to inform loved ones about a condition that can be so 'belittling' (Bates et al 1977, Herzog et al 1989, Norton 1989, Shaw 2001, Abrams et al 2006).

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Chapter 9: Findings

'Its like a Hush Hush thing'

Introduction

The previous chapter covered the normalisation of UI, and the emerging self-critique of this belief. Urinary incontinence has previously been regarded as a 'private' topic, one that is only discussed in medical consultations and not in 'other' environments. Some participants genuinely believed urinary incontinence to be a natural part of ageing and childbirth. This to a certain extent is true but, fortunately, there are options available which can help with such symptoms. Despite knowing about some of these options, many participants in this study felt restricted in accessing these services. Reasons for this will be explored in this chapter, which explores the 'privateness' of UI, the 'hush hush' concept the participants described. For these women in this study urinary incontinence became a hidden problem, which they managed themselves or with the help of professionals (for those who had sought help). It was apparent throughout the interviews that they felt very uncomfortable discussing urinary incontinence.

In general, many people would not want personal medical information to be known by others; especially if the information is regarding a sensitive subject like urinary incontinence. Many participants in the study stated, they would only disclose their urinary symptoms to female family members, because the causes of UI were related to the female genital area that should only be discussed with women, hence the second theme, 'it's a woman thing'. Disclosing or discussing female health issues with males was not culturally appropriate. As noted in chapter eight, many had been informed through childhood what was appropriate to discuss and what was not. Some women feared the reaction of their husbands. This will be the third issue to be discussed in this chapter.

Clear signs of embarrassment were noted in all the women interviewed:

'Its embarrassing telling someone you have this problem, what would you be thinking about me (Shagufta, 54 years old).

'I think even admitting to someone you have some form of incontinence is embarrassing. I mean I did not want to be interviewed first but I suppose if I can voice my opinions about something especially what I believe then why not but yeah the subject of incontinence is very important at the same time very embarrassing. It's like

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a personal problem you wouldn't want anyone to check you and explain to you that you have no control over your bladder its quite personal and embarrassing especially that I don't think doctors can do anything for you to be honest (Saleema, 35 years old).

'Hush Hush concept'

Participants commonly described feelings of self-consciousness, embarrassment, humiliation and disgust associated with leaking urine. Low self-esteem, shame, dirty and denial were also commonly reported.

'I feel horrible and think sometimes people can see it and smell it' (Farhat, 46 years old).

This was a common theme, and one of the main reasons why participants would conceal their problem, even from their loved ones, which inevitably caused barriers for many from seeking health care.

'I do sometimes get quite angry with myself I don't know why this is happening and things and with being angry I suppose I feel stupid as to why don't I seek help when it's not so bad, but I am scared what are people going to think [...]' (Farzana, 31 years old).

'Shit really. I always think I am only 28 how can this happen to me, obviously this is a common thing I know but people don't talk about it at all. So how are you suppose to know about it I wouldn't dare ask anyone, its really embarrassing so I just hide it cover it up with pads and regularly toilet myself. [...] I think every woman goes through incontinence and I am sure every man does too, but cause it's like a hush hush thing. I mean just say you have cancer down below you hear about breast cancer liver cancer and other illnesses but you don't really hear a women has cancer down below or a man. It's not really spoken about cause they are private things. I mean to say we live in a liberated society even stuff like that today is kept quiet' (Aisha, 28 years old).

The subject remained private to all participants. However it was apparent that for older women and those who had migrated into the UK, the whole area of urinary incontinence was one that related to the 'private area of the body'. Many would not use any terms to describe the vaginal area. Instead they would direct their gaze or use their hand to signal towards the pelvic region.

'It shouldn't be talked about [UI], because it is like talking about something so personal or private. A woman should not talk about this area [pointing towards pelvic area] to anyone' [...] (Saajida, 45 years old).

Saajida was then asked why she had decided to share her experience with me, to which the response was:

[...] well because you are a nurse and a lady, so you will understand what I am going through and may also help me. Its easier talking to someone that understands, and I can understand what you are saying' (Saajida, 45 years old).

Two important areas then arose for me to explore further, namely were the participants more comfortable discussing UI with a 'nurse' or with a 'woman' who has the ability to communicate in a common language of Urdu. These will be discussed in the next theme 'It's a woman thing'.

'It's a woman thing'

There was the common belief that health issues relating to women should only be discussed with women. It was common for these participants to discuss urinary incontinence and other health issues with their female family members prior to seeking any form of health care:

'I'd talk to my sisters and mum about it ... you see I know my mum has the same problem and my sisters sometimes say so too. It is just a women thing you discuss things, suppose it makes you feel better knowing it is not just you that has this problem' (Aisha, 28 years old).

'Because none of my own family is here, us daughter in laws talk about problems that we have with each other. Sometimes we also go with each other to the doctor, if I was back home I would speak to my mum before I even went to the doctors, but that is because we have to pay in Pakistan' (Naila, 26 years old).

Many took advice from the family members as to what management strategies to use:

'I told my sister in law who is older than me and knows a lot. She works in hospital. She told me she has the same problem and that I should wear these (shows tena lady pads). They are good but sometimes I have to change a few times a day'. (Tanzeela, 37 years old).

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'It's a woman thing'

There was the common belief that health issues relating to women should only be discussed with women. It was common for these participants to discuss urinary incontinence and other health issues with their female family members prior to seeking any form of health care.

I'd talk to my sisters and mum about it ... you see I know my mum has the same problem and my sisters sometimes say so too. It is just a women thing you discuss things, suppose I make you feel better knowing it is not just you that has this problem' (Aisha, 28 years old).

Because none of my own family is here, as daughter in laws talk about problems that we have with each other. Sometimes we also go with each other to the doctor. If I was back home I would speak to my mum before I even went to the doctor, but that is because we have to pay in Pakistan (Naila, 25 years old).

Many took advice from the family members as to what management strategies to use:

I told my sister-in-law who is older than me and knows a lot. She works in hospital. She told me she has the same problem and that I should wear these [shows tens lady pads]. They are good but sometimes I have to change a few times a day. (Farzeela, 37 years old).

Those participants who discussed UI issues with their family members also felt that talking about distress or worry were useful, in terms of feeling unburdened. *'It takes the weight of the mind and body if you talk about your problem'* (Sobia, 58 years old).

'Me and my mum and sisters are pretty close so I would discuss things with them and more then not I do get support. You know sometimes you just need to talk to someone and there are always there for me in what ever way which is nice not like I always take their advice but (pause) (Arifa, 37 years old).

This was not to say that all the women in the study felt discussing urinary incontinence with women was appropriate. For some, discussing this issue with anyone was a problem.

'No I have not told any one at home. They don't need to know, after the operation everything will be ok' (Sofia, 37 years old).

'My mum had this problem, and I went to the doctors with her. I remember docs saying something about exercise. It is just embarrassing how I can ask my mum what these exercises are' (Roshin, 28 years old).

'My family meaning my sisters and mum probably actually do have the same problem but its not discussed so [...] it's difficult really we are a private family anyway and things such as this are not discussed. Like I said its private' (Nadia, 37 years old).

There were clear differences between the participants. For some, discussing urinary incontinence with a family member meant unburdening themselves whereas for others discussing this topic was a 'no go area'. Confidentiality and privacy were repeatedly mentioned in the narratives. All believed it was inappropriate to discuss family issues, including health issues, outside the family home as this would bring shame to the family.

'Illness and problems should be kept inside the house and not outside, people talk about others and it is not nice when private things are discussed. I am only telling you because you are a nurse, and I know you can't tell anyone else about it' (Shahista, 54 years old).

Shame was a common theme, and one which has also been identified in previous research.

'How would I tell anyone, it is embarrassing for all I know I might have some serious illness' (Nadia, 37 years old).

'God I would never tell me friends about incontinence can you imagine they would think the same thing like I suppose I would if they ever told me would be disgusted about it don't you think' (Aisha, 28 years old).

'No no my friends don't know. I would never tell anyone something so personal outside the house. I have told you because you are a nurse and you might be able to help me' (Tanzeela, 37 years old).

Bhopal (1995) states Asian families are one of the most 'closed and private of all social groups'. Discussing matters outside the family home is not common. Jaswal and Harpham (1997) also state discussion is not common regarding health issues due to concerns of underlying health complications. Jik-Joen (2004) identified similar findings. In his study, 'saving face' is of great importance to many ethnic groups. Since youth, they are told to do everything possible to keep health concerns and family matters within their four walls, rather than lose face among their friends and relatives. For participants in this study, the whole issue of leaking urine was related to the 'private area', which some women found 'disgusting' to speak about. This sense of disgust was apparent through the interviews. Many of the women avoided eye contact, or would show emotions such as anger or embarrassment by laughing.

'In my opinion people keep quiet about urinary incontinence because of what other people start assuming. People see you at the surgery or hospital and think other things, which eventually become a big issue. That is why people hide illness' (Hajira, 21 years old).

'I have thought so many times to tell me friends it's just someone to talk to, but I don't have the courage to do it. What might they think, it's not something I would like to share with everyone' (Saleema, 35 years old).

Despite these comments, discussing urinary incontinence with a female health care professional was clearly not a barrier for these particular women. Exploring this concept further enabled useful insights to emerge:

'I have to say I would still prefer talking to a woman than a man about incontinence' (Farzana, 31 years old).

Some participants had approached their practice nurses with urinary incontinence whilst undergoing other health checks, such as for asthma and diabetes. However, many stated the practice nurses had informed them 'it was a norm':

'I have told her but she said it is normal for my age' (Fatima, 70 years old).

This account of professional attitudes in this area is supported by previous research (Mitteness 1990). The advice by health care professionals influenced many participants to live with their problem and for many the advice or reassurance they

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received was seen as reliable though sometimes in fact the advice turned out to be wrong.

'I told the nurse first and she said because I have asthma I cough a lot and the pressure makes me leak and it is normal, so don't worry about it ... So I just left it because I thought nurses know these things. I was wrong it got worse and worse that is when I thought no I have to do something about this. I put it off for so long. It got that bad sometimes when I had been to the toilet and got off, some more wee came out, after that I use to leak when I walked. I started wearing pads all the time and I still do. I told my doctor than and he shouted at me saying I should have come before. I didn't tell him what the nurse had told me, I don't want her to get in trouble' (Khalida, 42 years old).

'I told nurse; because I have asthma I have to see her a few times. So I told her and she gives me pads, you see when I cough it comes out and I cough because I have asthma...I suppose the nurse knows what she is talking about she must be right giving me the pads, if she hadn't I don't know what I would have done anyway' (Ghazala, 76 years old).

Participants preferred discussing it with a female health care professional, as many believed a woman would understand a woman. Discussing such a concept with males either health care professionals or their husbands was believed not to be suitable, as it is a woman's problem. These issues will be discussed in more depth in the next theme 'maybe he would leave me'.

'Fear and shame: Maybe he would leave me'

Many participants in this study stated they would not feel comfortable disclosing urinary incontinence to their husband or a male relative.

'I wouldn't tell anyone about this, especially not my husband. These things (pointing at pelvic/vaginal area) are dirty, because it's not right, what am I suppose to say, here son look I wet myself ... would you tell a man you had this problem? No child we Muslim women don't talk about private things, and I am sure that is what your mother has told you too' (Shenaz, 67 years old).

'No way! It is not a thing to tell your husband at all ... because it is so embarrassing in the first place. To be honest with you, my husband doesn't even know I have incontinence problems cause you know I wouldn't want him to think you know she has incontinence problems and she is young' (Saleema, 35 years old).

Only one participant claimed she would discuss UI with her husband. For this individual, UI was not considered a significant issue in the context of her other health issues.

'Oh yeah he gets to know everything (laughs) every detail whether he want to know or not I tell him everything he has no choice (Abeeda, 57 years old).

On average, less than 10% of women in this study (n= 14) would actually talk to their partners regarding their symptoms. The most common reason cited was the belief that urinary incontinence was normal and not considered to be a serious illness.

None of these women were comfortable with discussing this issue due to the social taboos surrounding the subject. Concerns of modesty required by women in Islam also played an important role. Many participants stated they had been taught from early childhood that discussing the genital areas, or gynaecological problems, with one's husband should be forbidden as it refers to the 'dirty' and 'privateness' of a woman, which was not to be discussed.

'I wouldn't want my husband to know ... there are some things I wouldn't discuss with him. If it ever got too bad than maybe I will, but now no. I will deal with it and I think I am ... Well no I wouldn't tell him ... he is a man. There are some things I would never discuss with my husband especially women problems'
(Khalida, 42 years old).

The few participants who did disclose that they would share their problems with their husbands indicated that they would to this because they felt lonely, or that they felt they could not discuss UI with anyone else, or that a leakage had happened in their partner's presence.

'Yes he knows [...] we were at home just me and him, and he told me to go and get him some water, when I stood up it all just came out on the floor. I was so embarrassed, he was sat there and I couldn't do anything [...] he got up and helped me clean it. I have a very good husband [long pause] (Nazia, 54 years old).

'I stopped going out and felt so lonely, that is when my husband asked what was wrong, and made me go to the doctors. I stopped going out and things, but really it is not that bad only when I cough or sneeze does it come out (Sofia, 37 years old).

Discussing female issues with male GPs was an issue for many participants. They believed if they discussed urinary incontinence with male GPs it would result in a physical examination.

'Firstly because he is male secondly I wouldn't want to be examined by him' (Arifa, 37 years old).

Kai and Hedges (1999) state the gender of health care professionals contributes to barriers between patients and professionals. The fear of examination can lead women to refuse health care. Participants in this study also stated that their

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symptoms were not severe enough for them to consult a doctor, even though many felt unable to cope with the management of this condition.

'My doctor is a man and talking about women's problems to man is not right I would get shy (pause) if get really bad I would but still it's not right' (Rashida, 34 years old)

'You must be joking! I would never see a man doctor for women's needs. The only reason I came to see [physiotherapist], is because she is a lady. If I have to go to see a man I wouldn't want any help at all' (Naila, 26 years old)

For those participants who had sought help, many stated they had consulted their GP about another condition prior to disclosing about leaking urine. The women who had sought help did so because of the severity of their condition. Discussing UI with their male GP was therefore less likely to matter, as the severity of the condition took priority over the gender.

'I will never forget when I told my doctor about it [UI]. I wished I could vanish. It got so bad I had to do something about it' (Ameena, 27 years old).

'I had to go to the doctors the problem was getting bad, I was shy because my doctor is man, but to me it doesn't matter if man or lady' (Shahista, 54 years old).

'Well we are not supposed to [be examined by a male], but if we have no choice then what can I do. Either leak everyday and not to anything about it. Or see a male doctor who can make me better, it is wrong but sometimes you have to swallow your pride if you need help. Even before this I have seen so many men doctors not for leaking urine but generally and they had to do examination on me too. Trust me after the medical problems I have had you don't care who looks at you, you just want to get better and get out of there. I mean come on doctors don't remember all the women who they have seen, well all the bits they have seen do they. I just think for our Muslim women providing a female doctor would be great, women that need help like my mum would go' (Roshin, 28 years old).

*'Going to a man is against my religion as no man but your husband should see you in that condition, but if it became that bad and I had to go to a man than **I would have to ask my husband or probably take him with me**'* (Salma, 26 years old).

The highlighted quote indicates the reason why many participants do not discuss urinary incontinence or any female genital condition with their partner. However, according to Al-Misri and Keller (1994), Muslim women are not formally restricted in any way when seeking health care. If no female doctor is available health care should be sought from a male practitioner with the permission and accompaniment of their male relatives; their father (for the unmarried) or their husband (for the married). Indeed, participants stated approval from their husband was of great importance to them, especially where examination was necessary:

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You must be joking! I would never see a man doctor for women's health. The only reason I came to see [physiotherapist] is because she is a lady. If I have to go to see a man I wouldn't want any help at all (Naila, 20 years old).

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'Firstly my husband wouldn't approve of being examined by another Asian male. I think its probably the way he think which has probably got something to do with our religion its just the fact that no other male should be seeing me especially after I am married besides my husband. If I need to be examined, it should be by a woman whether she was Asian or not, it is just the way we have been brought up really. For example when I was living with my mum and my dad every time I went to the doctors I was well my mum expected me to be seen by a female than a male and I believe that is more culture than religion we tend to follow what our parent and their parents did' (Noreen, 26 years old).

Many participants voiced the concern that if their husbands forbid them to seek health care from a certain doctor, they felt they could not seek help. Key (1987) highlights health care-seeking behaviour in Indian women is greatly determined by the permission from husbands or mothers-in-law, social taboos and cultural restrictions, all of which influence whether, when and which kind of services women access.

'I would need to tell my husband if I went to a male doctor [...] I know very well that he would refuse' (Fozia, 26 years old).

Shaikh and Hatcher (2004) have also commented that since men are decision makers and in control of all the resources, they decide when and where women should seek health care. Women are usually restricted in their own decisions when they are seeking health care or attending consultations unaccompanied where health professionals are males.

'I would ask for my husband's permission because it's wrong not to tell your husband that a man doctor is going to examine you. I would take my husband with me you know what the men in our community think about things like that. Well that they should be told everything you do especially when you need an examination' (Arifa, 37 years old).

'I think my husband would be very upset ... like I said he wouldn't want me to go to a man doctor if it was a lady it would be fine, and I wouldn't go against what my religion says' (Ameena, 27 years old).

In general, participants felt that discussing female health concerns with their partners was not culturally correct. Participants themselves did not instigate help-seeking behaviour, as many expected family members to advise them, persuade them, or insist that they go, or actually take them to consultations.

'My daughter has been very understandable, the one you saw at the teaching session that day. They were the ones that told me I had to do something about this problem. They came with me to the doctors, and also to the big doctor at the hospital, if they did not I don't think I would have gone to see anyone about it [...] It was only when my daughter noticed it, she forced me to tell my doctor' (Farhat, 46 years old).

Summary

In this chapter, it can be seen that the nature of the subject area of UI was embarrassing and degrading, which prevented many disclosing feelings about it or also its presence to their loved ones. In this study, shame and embarrassment have been reported as barriers to help seeking in conditions such as incontinence and sexually transmitted disease. The sensitive nature of discussing urinary incontinence was clearly articulated by one participant:

'Well it is not really a talked about subject is it here is it. I mean you do not get people just talking casually about incontinence really I mean it's not a good conversation topic is it. I mean if people did discuss it something can be done there and then. I think it would be a good idea to talk about it with women who have the same problem um you can bring out different issues but they don't want to say it, cause they think no one else has it and if I admit to it, people are going to laugh at me. When you think of incontinence well not incontinence but not having control over your bladder, you automatically think of babies as they wet their bed or something. If someone older says, they cannot control their urine then its like, oh my god but we do not know someone else may have it too, but you need that courage to stand up and say yeah I have or had incontinence and this is what I did about it. You would not go into a group and say that, because it is quite embarrassing really and this is where I think culture plays a big part. I mean you are taught from a young age what can be discussed and incontinence is not one of them, but we need to I suppose break away from some of them thoughts. However, in Islam and this is written if something is upsetting you or bothering you in the medical instance then you should seek help but you should not go for help because it's a man or you are not really ill I mean incontinence doesn't kill like cancer' (Aisha, 28 years old).

Participants seemed to feel that urinary incontinence was a female problem, one that should not be discussed with any male family members or male doctors. UI was related to the female genital area, an area that many regarded as 'dirty' and 'private'. The privateness was seen through the narratives as many refrained from using terms to explain, rather they used hand gestures or eye contact instead.

Disclosing symptoms of UI to me was not an issue, as my professional background and my status as a woman allowed women to discuss 'female issues'. However disclosing symptoms to health care professionals for many meant 'examination' where undressing would be a necessity. As many of the participants had male GPs this caused a barrier to seeking health care. For those that had sought help the component of severity overtook gender issues, although many were clearly embarrassed.

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Chapter 10: Findings

'Its not cancer': 'urinary incontinence is not life threatening'

Introduction

The previous chapter related the participant's narratives to 'the hush hush' nature of urinary incontinence. In this chapter, I will bring together various strands of the study that relate to why these women believed such conditions should remain behind closed doors. In the previous chapters, factors that generally affect South Asian Muslim women were covered. There will be some overlap of these issues in this chapter, but the specific focus is UI. This chapter primarily relates these responses to the upbringing of the participants, from childhood to adulthood, which has created a specific social governance framework that dictates how to behave in given situations. Gadamer refers to this process as 'effective history' (Gadamer 2004, pg 300), referring to his theory that our historical past is fundamental to our being-in-the-world. Under his theory, Gadamer states that individuals are unconscious of the traditions of their past, and of the way they have an affect on their lives (pg 306).

In this chapter, I will consider aspects of help-seeking behaviour which indicate the health related processes and decisions the participants disclosed concerning their health, with specific reference to UI. The chapter is titled 'It's not cancer', as participants felt UI was not a serious condition. Many of them had other medical conditions such as asthma and diabetes, which, for them, outweighed the importance of UI. Two main issues are covered in this chapter. The first refers to the view of the participants in relation to health and illness, and how they interpreted illness, usually within their Islamic perspective. The second issue concentrates on factors that many women felt restricted or caused barriers to seeking health care, relating mainly to communication issues.

As Islam was the referential framework for women in this study, it would be appropriate to begin this chapter with the influence of religion on help-seeking behaviour.

'Allah will not let me suffer'

All the participants talked about Islam very passionately. Generally every participant felt that for every illness there is a cure (Al-Misri and Keller, 1994). As Muslims, they

are encouraged in their faith to seek treatment, especially if ill health caused a barrier to them continuing with their daily religious obligations.

'If you have an illness or something it is from God but God has given us the brain to work out the solution for each problem or illness. Ok sometimes there may not be a cure but Allah will not let you suffer' (Tanzeela, 37 years old).

'Islam encourages you to make yourself better that is what is written. You should not suffer, or wait for someone else to take you to the doctors. God has given us the knowledge to seek help and we should. For me my health is important, because if I am not well I cannot pray and that is not good' (Khalida, 42 years old).

Participants commonly carried out supernatural remedies such as praying and seeking advice from a spiritual leader or self-care strategies for dealing with illness, whether for general ill health issues or leaking urine. Only when symptoms became unbearable did participants seek help, through a Peer Saab (spiritual healer), through performing prayers, or via medical conventional treatments. All the participants implied that 'good and bad health is from God, and God will send me a cure, and protect me':

'I leave everything to God; my Allah will help me in ever step of my life. I have always told my children the same thing, leave things to God because God is the only source of power that gives you what you want, you should not fight it. I have tried to live my life the way a Muslim is suppose to, I do not cause anyone any problems and that is what our religion says and that is what I do, I am totally devoted to my God' (Nazia, 54 years old).

The importance of religious traditions and spirituality was a means of coping with illness and distress. Participants referred to their belief systems as a means of making sense of their situation and a fundamental aspect of their lives. Common practice within the Pakistani culture is to maintain contact with a spiritual leader. Pakistani Muslim women in this study stated they had consulted with their 'Peer Saab' issues regarding ill health and also 'UI'.

'I even asked a Peer Saab he said the same thing, I have an infection [...] he said I should pray and things, but how can I when I leak. That is when I decided to go doctors. Doctors have medicine for everything, you only get medicine for an illness, Peer Saab was right I have some kind of an illness; otherwise I would not be on these tablets' (Ghazala, 76 years old).

The process of consulting spiritual leaders first has been seen in previous research as a cause of late presentation of illness, when symptoms have become progressively worse (Freidman et al 2006; White et al 2006). Such an act from the believers' view, however, can be seen as a source of inspiration and encouragement

are encouraged in their faith to seek treatment, especially if ill health caused a barrier to their continuing with their daily religious obligations.

If you have an illness or something it is from God but God has given us the brain to work out the solution for each problem or illness. Ok sometimes there may not be a cure but Allah will not let you suffer (Tanzeeb, 37 years old).

Islam encourages you to make yourself better than what is written. You should not suffer, or wait for someone else to take you to the doctor. God has given us the knowledge to seek help and we should. For me my health is important, because if I am not well I cannot pray and that is not good (Khaleida, 42 years old).

Participants commonly carried out supernatural remedies such as praying and seeking advice from a spiritual leader or self-care strategies for dealing with illness, whether for general ill health issues or feeling unwell. Only when symptoms became unbearable did participants seek help, through a Peer Saab (spiritual healer), through performing prayers, or via medical conventional treatments. All the participants implied that 'good and bad health is from God, and God will send me a cure, and protect me'.

I leave everything to God, my Allah will help me in every step of my life. I have always told my children the same thing, leave things to God because God is the only source of power that gives you what you want, you should not fight it. I have tried to live my life the way a Muslim is supposed to, I do not cause anyone any problems and that is what our religion says and that is what I do. I am totally devoted to my God (Nasir, 64 years old).

The importance of religious traditions and spirituality was a means of coping with illness and distress. Participants referred to their belief systems as a means of making sense of their situation and a fundamental aspect of their lives. Common practice within the Pakistani culture is to maintain contact with a spiritual leader. Pakistani Muslim women in this study stated they had consulted with their 'Peer Saab' (spiritual leader) regarding ill health and also 'U'.

I even asked a Peer Saab he said the same thing, I have an infection [...] he said I should pray and things, but how can I pray. That is when I decided to go doctors. Doctors have medicine for everything, you only get medicine for an illness. Peer Saab was right, I have some kind of an illness, otherwise I would not be on these tablets (Ghazala, 76 years old).

The process of consulting spiritual leaders that has been seen in previous research as a cause of late presentation of illness, when symptoms have become progressively worse (Friedman et al. 2006; White et al. 2006). Such an act from the believers' view, however, can be seen as a source of negotiation and encouragement

to seek help. For example in the above narrative by Ghazala, it was her Peer Saab who had encouraged her to consult her GP, as he informed her that she may have a serious illness. Without such encouragement Ghazala's condition could have got worse, and maybe she would not have sought help. Kleinman (1980) and Helman (1994) have stated non-Western cultures are more likely to consult the social or supernatural spheres first, whereas the Western focus is on the individual mainly seeking health care through medical professionals.

Spirituality has been explored as a way of coping with illness. Prayer and reflection helps an individual to make sense of ill health or well-being (Baldacchino and Draper (2001). Rassool (2000) elaborated further and stated illness and reflection can help individuals to grow spiritually, a concept that is in harmony with Islamic belief.

'Good and bad is from Allah'

In the same way that people have beliefs about health they also have beliefs about illness. According to Ogden (2000), practices and beliefs about illness appear to follow a pattern and are made up of five factors. Identity, consequences (beliefs about seriousness), timeline (how long it will last), cause, and cure/control (medical interventions). Many of the participants in this study believed that illness was a test from God or a punishment for their sins (Athar 1998). Muslims understand illness, suffering and dying to be a part of life and a test from Allah. In Islam, illness is also regarded as a test of how strongly a person believes in God.

'I have tried to help myself and nothing is being done. It is best to leave everything to God now, good and bad is from Allah and we need to leave everything to Him. God sends you a problem and God will only send you a cure. I have just left everything to him now' (Nazia, 54 years old).

'I have so many problems, I have not been able to pray for so many years because of this [leaking urine], what have I done that is so wrong, I just feel like I am getting punished, but for what (cries)' (Hameeda, 46 years old).

According to Greenhalgh et al (1998) health and illness can be interpreted and explained in terms of personal experience and expectations. For example, this relates to how to be healthy, how to recognise illness and how to be ill.

'Good health and bad are both from God. God does not punish us for anything, but sometimes tests us. For a Muslim to pray from their heart and mind you need to be

healthy, and if something is coming between me and praying like illness then I will do something about it like go to the doctors' (Shenaz, 67 years old).

'Allah states when you are ill, he will send you a cure whether that is in the form of a doctor. You need to stay healthy to be religious, and to me this is very important if something is coming between me and my Allah and me and my prayers, then Allah has given you that strength to go out and find help' (Farhat, 46 years old).

Being healthy for the participants in this study meant not taking any regular medication and having time to exercise. Twenty-seven women in the sample had at least one other medical conditions apart from urinary incontinence. Twenty-three participants took regular medication, and, overall, most rated their health 'poor'¹⁹. Medical conditions consisted of diabetes (six participants), asthma (14 participants), recurrent UTI (two participants), and hypertension (six participants). Other related conditions were, obesity, arthritis, angina and related conditions, digestive problems, general weakness, stroke and arthritis, all of which can contribute to the development of urinary incontinence (Thomas et al 1980; Vetter et al 1981; Hunskaar et al 2000). Due to these other medical conditions many participants felt urinary incontinence was the least of their problems, as it was not life threatening.

Although Islam encourages Muslims to seek help there were clearly restrictions that many Muslim women felt had to be considered. This related to the gender of the health care professionals (Al-Misri and Keller, 1994 pg 510-514) and communication. Patient preference for a female doctor can be influenced by many factors, especially when the patient is presenting with a problem in the female genital area. According to Brink-Muinen et al (1994), women find it easier, or less embarrassing, to talk to women because of feelings of shame and fear, and taboos about genital problems.

'I think it would definitely be better if there was a lady doctor available it gives people that choice. Some Muslim women would only want to be seen by a lady and us as professionals need to respect that, whether they are Muslim, Jews, Christians, purple pink or green. It's more about having an open mind not a restricted vision about people. We are providers of a service, so we should provide. But I suppose that is what I think, the NHS is stretched, but it would be nice' (Saleema, 26 years old).

'It's going against my religion'

When accessing health care services the sex of the doctor will always be a concern to many Asian women (Gray 1982). As found in Nazias' narrative:

¹⁹ No tool was used to measure the health of the participants; this was their own definition of their health.

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'No child that is wrong we cannot do that [being examined by a male doctor] I will not go against what my religion says [...] I will ask for a woman, if one is not around than I will not go I will have to live with it my problems' (Nazia, 54 years old).

Many of the participants felt seeking health care from a male health care professional was strictly forbidden in their religion, and for this reason they refused to seek health care:

'Um only when I'm going to see a male GP um (pause) well if they need to do a check up on me meaning me taking my clothes off I'd be a little bit restricted there [...]. You see in Islam a women should not be examined by a male doctor, especially when it comes to vaginal examinations and things, it should not be done' (Noreen, 26 years old).

The fear of examination and the modesty required by Muslim women played a major role in seeking help. Examination by a male professional can be distressing for any woman, due to embarrassment and exposure. Regardless of whether they were born in the UK or elsewhere, most women in this study stated that they would put up with any illness, but would not let a male doctor or nurse examine them.

Day's (1994) findings also correspond with this study. Importance is placed on the preservation of women's dignity, resulting in hesitancy to be touched by male practitioners.

'Yeah it's not right I mean if I did go to the doctor with this he would want to check me and being a woman and exposing yourself to a man is not right its against our religion and I wouldn't go against my religion' (Aisha, 28 years old).

Islam places a high value on direct human contact and interaction (Rassool, 2000).

Given their modesty and the importance of it, it is not surprising that women were reluctant to ask their doctors about urinary incontinence due to the fear of examination.

My religion teaches us as woman not to expose yourself in front of any man besides your husband I feel embarrassed exposing in front of him never mind anyone else (laughs). It's wrong and I wouldn't be able to do that see if its necessary like when I gave birth there was a male doctor there of course I was embarrassed but that was necessary but this is not' (Arifa, 37 years old).

'Women doctors for women's needs'

Participants who had migrated from India or Pakistan felt disadvantaged due to their inability to communicate. Many noted that receiving health care from their own

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Many of the participants felt a strong feeling of shame and embarrassment
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necessarily but this is not (Fatima, 37 years old).

Women doctors for women's needs

Participants who had migrated from abroad to the UK, and who had
inability to communicate. Many noted a language barrier that made it

countries cost money, which restricted access to specialist consultant, but which allowed for choice in gender of the health care staff. The issue of being placed on the waiting list was also a concern with the health care system in the UK.

'In our country we have women doctors for women's problems. Like here we are registered under doctors, we are not in Pakistan. We can go to whichever doctor, like if there was a problem with your heart that is where you would go but if you need to see a woman doctor then you can' (Sobia, 58 years old).

'I wish I had gone to Pakistan and got the operation done ... well I would pay and get seen straight away, I would get a woman doctor too. But my daughter told me to go to the doctors, because I don't have plans to go to Pakistan soon. I will wait for some time, my next appointment is in January and if nothing happens by then than I will go and get treatment done in Pakistan' (Nazia, 37 years old).

'The bad thing is if we were in our own country than we would be able to see a male or female doctor but here we don't get a choice because the health service is free here, but over there we have to pay so the choice is yours' (Hameeda, 46 years old).

'My problem is not that bad'

There was clearly a relationship between symptom severity and help-seeking behaviour. Previous studies have found that the perception of incontinence as a problem was one of the strongest predictors of seeking treatment. This study supports such observations. Participants reported that the reason UI was disclosed to a doctor was 'if it got worse', or if there was 'fear of a serious underlying cause' (usually cancer), or if the UI led to 'restrictions on continuing religious obligations'.

'I mean my health is really important to me I'd hope that the problem didn't get any worse but obviously things untreated get worse (laughs) um but I think if it did get worse finger cross it didn't (laugh) I'd probably end up seeking help' (Hajira, 21 years old).

'I mean I will go to the doctors if I thought my incontinence got any worse but that is my definition of what or how bad I would class my incontinence. In my life I have put up with so much it like its my life and I'll deal with it I wouldn't want to burden anybody else about it to that I don't want to be a trouble to anybody. If I can mange it I will manage but if I cant I will do something's about it I'll try my pelvic floor exercises (laughs) again (laughs)' (Abeeda, 57 years old).

Almost half of the participants presented a rationale for not seeking help. The most important were that incontinence is age-related, and their condition was manageable. Comments included 'I am getting old now', 'I have heard people saying when you get old it happens', 'my mother-in-law has this problem too', 'you see if my problem was worse then I would', 'at the moment I can cope'. Leaking urine for these women was mainly understood as something related to their genital area, therefore seeking

countries cost money, which restricted access to specialist consultant, but which allowed for choice in gender of the health care staff. The issue of being placed on the waiting list was also a concern with the health care system in the UK.

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health care was not comprehensible in terms of their cultural and social context, and many self-managed.

'I just smile and nod'

Communication was a fundamental component of seeking health care. Out of the 41 women in the study, 31 were born outside the UK. Of these, two had migrated to the UK at a young age and had had their education here. For the remaining 29 women who had migrated communicating in English remained an issue. Many who had migrated from India or Pakistan had begun ESOL classes to improve their ability to communicate but still felt disadvantaged. The remaining ten participants all had formal education in the UK.

'I have learnt English not as good as yours but I do understand and little bit speak as well, its hard sometimes to understand, but I try. Oh yes communication is the biggest barrier and I do believe I do have a advantage I mean for someone like my mum she needs to rely on us but something's you wouldn't want other to know even your own kids' (Abeeda, 57 years old).

'I learnt English here at classes in the community centre. I could speak a little bit before, but it different from yours. It took me a long time to fit in but I have now better. I learnt English too. In India I learnt English but here is was different. If you can't speak like everyone else you cannot fit in well here I found that out quite early on. Lucky my husband supported me and let me go to English classes. I've been looking at other days too' (Sadia, 27 years old).

Communication is a fundamental part of any prevention or treatment method. Similarly, ability or inability to communicate independently was a factor for compliance or non-compliance to treatment. Compliance to any form of treatment requires an individual's mental ability to understand, cope and manage the problem. Barriers that influence whether patients seek or continue treatment include communication problems between patients and providers, cultural and attitudinal factors, lack of information and lack of knowledge (Rawlings-Anderson, 1992).

The inability to communicate in English was a concern. Fears of feeling belittled and low self-confidence all caused barriers to seeking health care. Although many had learnt basic English, the confidence to communicate directly with health professionals was low.

'Who is going to listen to me I can't even speak English who is going to listen to an Asian woman if she can't speak English. I sometimes wish I could speak it' (Nazia, 54 years old).

For these reasons, family members accompanied women in the study to consultations:

'My sister-in-law when I came here first she is better at English than me she has been here for longer time but now I can do myself because I think my English not so bad I went to classes to help me speak, reading sometimes is problem' (Rashida, 34 years old).

'I couldn't speak English then when I came to the country so it was hard and I use to take someone with me all the time I always took my sister-in-law (laugh) yeah my big sister-in-law' (Rukhaiya, 37 years old).

The use of family members in consultations was a common finding in this study. However this can cause problems, due to the poor levels of interpretation, misinterpretation and misdiagnosis by the health care professionals and those accompanying the patients. Those participants who had difficulty with communication felt that it was their children's responsibility to accompany them to consultations, as stated by Ghazala:

'My children have to come with me. If they couldn't then I would not go to the hospital. When we get old our children have to look after us' (Ghazala, 76 years old).

For others being accompanied by their children who were fluent in English gave them a sense of pride:

'My daughter always comes with me; they [health professionals] speak so fast I can't understand what they are saying. My daughter goes to university she is doing a degree so she understands everything they say' (Farhat, 46 years old).

It was a common belief for those in the study that people born in the UK would understand medical terms. Participants who were fluent in English also felt it was their duty to accompany the elders in the family to medical consultations:

'I am still to this day working as an unpaid interpreter for my parents not just for health things but others things too' (Arifa, 37 years old).

For others, accompanying their relatives meant disclosing personal information:

'I have been with my in laws, to help. It makes it embarrassing sometimes because they need to ask personal questions. What do you do ask them or just ignore it' (Ameena, 27 years old).

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all. Such questions were usually related to bodily taboos, which has a particular significance for this study. .

'Urdu is pure Urdu'

Non-verbal communication was as important as verbal communication for accessing health care. Providing translated health information was not believed to be sufficient for many of the women in this study, as a high percentage were unable to read the common language of Urdu, or any other Asian written language:

'I can't read Urdu or Punjabi. When I went to the hospital they [professionals] gave me paper in Urdu and Punjabi. I took it, but I can't read it [...] I am not going to tell them I can't even read my own language. So we just came home. I don't know anything about this problem; I just want it to go away' (Tayiba, 63 years old).

For embarrassment reasons many people deny the inability to read and write in the native South Asian languages or the common written form of Urdu. Many participants preferred to be verbally informed about health issues rather than admit their literacy issues:

'She [physiotherapist] gave me leaflet in Urdu, I told my daughter to tell her I would like English, because then my daughter can read it to me' (Farhat, 46 years old).

Some felt that the resources that were available were written in such a format that they hindered understanding even further:

'Well no because they are not available that widely. I mean there will be six leaflets in English, which I can understand, as there are a majority of White people and these people read that English. But if you look at somewhere like Blackburn or Accrington the majority of the population are ethnic but everybody keeps going on about it but no one really has any resources to fulfil this requirement. Stop talking about it and get something done about it. When they write in Urdu its pure Urdu which nobody understands, its like for example if you started to write in the 'Queens English' you wouldn't get the majority of the public to understand it. Whereas if you wrote I mean in English we write what we speak so the majority understand it and speak it whereas if you get Urdu leaflets they are wrote in such pure Urdu the majority don't understand them anyway' (Aisha, 28 years old).

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'They are very vague and some of the words used are inappropriate. I think, I mean some of the words that are used are not words that people would use daily, they are quite complex and hard to understand and some words you just cant translate you know. [...] (pause) well urinary incontinence what is the translation for that if I was suppose to explain to my mum what it was I wouldn't be able to cause I wouldn't know what words to use in Urdu or Punjabi' (Rukhsana, 39 years old).

Following on from Rukhsana's quote above the Urdu dictionary was consulted to seek the term for urinary incontinence, together or as two separate words. The term urine [waste fluid discharge from the body] and urinate [pass urine] were found. However, incontinence was not a term within the Urdu dictionary (Qureshi, 1988). This indicates that a general lack of knowledge or 'hush hush' nature of leaking urine can restrict many seeking health care. If such terms are not within the Urdu, Punjabi or Gujarati vocabulary then it is understandable that these groups are unaware of them.

'Only if they could speak our language'

All the women in this study had 'Asian' GPs who had the ability to communicate verbally in Urdu. Similar ethnic backgrounds were noted as a preference as they would be more likely to understand cultural and religious beliefs.

'My doctor is very good he speaks our language. He is not Muslim like me, but comes from India so he knows how we live' (Farhat, 46 years old).

Kumar et al (2005) found in their study that more than half the sample preferred or had the need to discuss their illness or condition in their own languages, which may be related to cultural and linguistic bonds between them. This may have been also the reason many women in this study voiced a belief that health care professionals from similar backgrounds would understand the way participants lived their lives, a belief also found by Waitzken (1991).

'Being honest when you have to explain something to doctor then its finding the words and when you speak it sounds really silly what you are trying to explain to the doctor it makes it easier to laugh and the problem doesn't seem as serious to them' (Farzana, 31 years old).

As most participants had a limited command of English, the overall importance when consulting health care professionals was that of sharing similar cultural beliefs and communicating in a language common to both the patient and health care professional.

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'Only if they could speak our language'

All the women in this study had Asian, GPs who had the ability to communicate verbally in Urdu. Similar ethnic backgrounds were noted as a preference as they would be more likely to understand cultural and religious beliefs.

'My doctor is very good he speaks our language. He is not Muslim like me, but comes from India so he knows how we live' (Farhat, 46 years old).

Kumar et al. (2005) found in their study that more than half the sample preferred or had the need to discuss their illness or condition in their own language, which may be related to cultural and linguistic bonds between them. This may have been also the reason many women in this study voiced a belief that health care professionals from similar backgrounds would understand the way participants lived their lives, a belief also found by Wainman (1997).

'Being honest when you have to explain something to doctor then is finding the words and when you speak it sounds really silly what you are trying to explain to the doctor it makes it easier to laugh and the problem doesn't seem as serious to them' (Farzana, 31 years old).

As most participants had a limited command of English, the overall importance when consulting health care professionals was that of sharing similar cultural beliefs and communicating in a language common to both the patient and health care professional.

On the other hand, some participants (especially those born in the UK) felt that a GP with similar cultural or religious backgrounds as themselves could cause restrictions, due to substantial differences that may exist because of separate perspectives. These women preferred non-Asian doctors, but had never considered changing their GP:

'Yeah because just say for instance you went cause you wanted to have an abortion and the doctor was Muslim like yourself and had strong beliefs, then you would not be able to abort a child. God gives life (pause) people easily judge those that are like themselves if you don't follow the same religion then you don't know (pause). So for me I would say definitely the gender is an issue and yes to some extent the ethnic background' (Arifa, 37 years old).

The findings of Hennink et al (1998) relate to this study, as they also found Asian women showed a strong preference for a female GP and a non-Asian GP for sexual health and contraceptive service.

The role of the practice nurse within a GP surgery is to conduct clinics, such as asthma, cardiovascular, diabetic, and well woman. All the women in this study had accessed these services at some point. All practice nurses they had encountered were from the White majority population and none spoke any other language but English. Participants who had difficulty in communicating in English stated they would generally nod and smile at the practice nurses as a way of stating they understood what was being said, although many stated they did not understand what was conveyed.

'When I have been, I just agree, well nod, I don't understand what they [nurse] say' (Ghazala, 76 years old).

Summary

Communication issues and the gender of the health care professionals were the major factors influencing Muslim women seeking health care services for urinary incontinence or women's health issues. Many participants were 'fixed' in their views and practices. This was despite the fact that many stated that culture is not a fixed concept. In fact, for most participants in this study, culture was an unchanging process, as many related cultural practices directly to their religious obligations. Indeed, for some cultural practices that were seen as going against what 'God' asks of his followers were seen as a sin that will never be forgiven.

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Summary

Communication issues and the gender of the health care professionals were the major factors influencing Muslim women seeking health care services for urinary incontinence or women's health issues. Many participants were 'fixed' in their views and practices. This was despite the fact that many stated that culture is not a fixed concept. In fact, for most participants in this study, culture was an unchanging process, as many related cultural practices directly to their religious obligations. Indeed, for some cultural practices that were seen as going against what 'God' asks of his followers were seen as a sin that will never be forgiven.

Culture affects every aspect of an individual's life, including health and illness. The way an illness or condition is viewed very much depends on what an individual perceives as an illness, and the appropriate way to react to it. According to Mead (1955), this would also apply to behaviours and attitudes about urination. For the participants in this study, the impact of culture, religion, the perceived seriousness of urinary incontinence as an illness, examination by male doctors and communication all became part of the overall decision to engage, or not, in health care activities.

This chapter indicates that many participants believed urinary incontinence was not a serious illness as it is not life threatening. Seeking health care for such a condition was seen as inappropriate, especially as many felt examination was inevitable, usually by male GP's.

The balance towards seeking formal health care shifted when UI began to restrict their ability to perform prayers and other religious duties. At this point, issues of communication, gender and ethnic equivalence began to weigh in the scales. The ability to communicate independently for many of the participants was a desire, as being accompanied by other family members meant that information about their health was disclosed. For this reason many of the participants were registered with general practitioners who had the ability to communicate in a common language, usually Urdu or Hindi.

However for those participants who had sought help performing prayers had become more important than examination by a male health care professional, or communicating independently. This next chapter will discuss these issues further.

In the next chapter, I will draw upon the narratives of the fourteen women who had sought help from continence services, and discuss how they viewed the services they received.

Chapter 11: Findings

'Get myself checked out'

Introduction

In the previous chapter, it became apparent that the participants in this study did not classify urinary incontinence as a 'real' illness. Real illnesses for these participants were those that affected their overall health negatively and where medication was prescribed. Out of the 41 participants, 26 women in the sample had other medical conditions, which they felt were more serious than UI. Seeking health care for urinary incontinence was the least of their concerns.

Participants also repeatedly mentioned the influence of their God in relation to health and illness. Some welcomed ill health and sickness as they believed this was a blessing, a way of cleansing the soul of sin.

The previous five finding chapters have drawn on quotes from all 41 participants. In this chapter, I will only consider views and opinions of women who had sought help from continence services. This chapter will address some of the issues these women who had sought help faced. Through their narratives it will become clear how these women perceived, accepted, and understood the service they received. I will also consider issues that many faced when seeking health care for other medical conditions, and not just urinary incontinence. Fourteen participants in this study had sought health care. They were at different stages in the care pathway. For example some of the participants who had sought help were at the behavioural techniques which consist of learning pelvic floor exercises, bladder training, regular toileting, and fluid management. Whereas other participants were more advanced in their needs and therefore were at the surgical stage.

To begin with, I will consider what prompted these women to seek health care. Following on from this the role of the physiotherapist, the nurse specialist and the consultant are considered. Compliance and non-compliance to the treatment regimes will also be reflected upon.

'Get myself checked out'

All fourteen participants who had sought help did so because their symptoms had become progressively worse, and had caused a barrier between them and their

Chapter 1: Findings

'Get myself checked out'

Introduction

In the previous chapter, it became apparent that the participants in this study did not classify urinary incontinence as a 'real' illness. Real illnesses for these participants were those that affected their overall health negatively and where medication was prescribed. Out of the 41 participants, 28 women in the sample had other medical conditions, which they felt were more serious than UI. Seeking health care for urinary incontinence was the least of their concerns.

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To begin with, I will consider what prompted these women to seek health care. Following on from this the role of the physiotherapist, the nurse specialist and the consultant are considered. Compliance and non-compliance to the treatment regimes will also be reflected upon.

'Get myself checked out'

All fourteen participants who had sought help did so because their symptoms had become progressively worse, and had caused a barrier between them and their

religious obligations. All these women were at different stages in the treatment plan, some at the non-surgical stage and others at the surgical stage.

In general, people who seek health care for urinary incontinence will potentially pass a three-stage chronological process: diagnosis and assessment; conservative management; and finally, if needed, surgical management (DoH, 2000).

All fourteen help-seeking participants had begun the process through their GP, although the consultations that led to a diagnosis of UI had been primarily for another condition.

'I told my doctor because it was getting worse, sometimes I can stand up and it use to come out [...] My daughter told me to go to our doctors, so I went but I was shy' (Khalida, 42 years old).

Communication was not an issue at this initial stage of seeking health care, as the GPs usually shared the common language of Urdu:

'Well it was easy I could just tell him, and didn't have to take anyone with me. He told me I should go and see the nurse at hospital who will help me' (Farhat, 46 years old).

All participants were referred to continence care services. According to the NICE (2006) guidelines for urinary incontinence, initial assessment of UI should be performed by the general practitioner, which would include medical history and a physical examination. Ghazala stated that such assessment was not carried out and her GP had not informed her of the reasons for referral:

'She [GP] told me I had infection here (pointing to lower abdomen and back), and said I had to see someone at the hospital [...] no she did not check my urine' (Ghazala, 76 years old).

Others felt that their GP was very reassuring regarding the condition, and provided reasons as to why the participant may have urinary incontinence:

'He [GP] told me he was going to send me to the hospital; I panicked then thinking something was wrong with me. But my doctor explained to me it was not bad but I had to get myself checked out by a special doctor [...] he told me sometimes this happens in women because of giving birth and because I have asthma as well I always cough too' (Khalida, 42 years old).

Options for treating urinary incontinence fall into four main categories, behavioural techniques, medications and devices and finally surgery. Usually the non-invasive techniques are considered first, however the treatment options will vary according to

religious obligations. All these women were at different stages of their lives, some at the non-surgical stage and others at the surgical stage.

In general, people who seek health care for urinary incontinence follow a three-stage chronological process: a first stage of self-management, a second stage of management and finally, if needed, surgical management.

All fourteen help-seeking participants had sought help for urinary incontinence although the consultations that led to a diagnosis were not always successful in the condition.

I told my doctor because I was getting worse and worse and I was not able to come out [...] My daughter told me to go to a doctor [...] I went to a doctor (Hafida, 42 years old).

Communication was not an issue at this stage as the doctor and patient spoke the same language and the doctor usually shared the common language.

Well it was easy, I could just tell him and I told him I had urinary incontinence and he told me I should go and see the nurse at the hospital and I went to the nurse and she told me I should go to the doctor (Hafida, 42 years old).

All participants were referred to continence care at some point in their lives. (2008) guidelines for urinary incontinence state that assessment of urinary incontinence should be performed by the general practitioner, which could include a physical examination. Gizaia stated that such examination was not performed and that her GP had not informed her of the region's continence care services.

She [GP] told me I had infection here [pointing to the bladder] and I went to the hospital and I had to see someone at the hospital [...] I went to the hospital and I had to see someone at the hospital (Gizaia, 76 years old).

Others felt that their GP was very reassuring regarding the condition and the reasons as to why the participant may have urinary incontinence.

He [GP] told me he was going to send me to the hospital and I was going to have something wrong with me. But my doctor said to me that I was going to have something wrong with me. I had to get myself checked out by a specialist. I went to the hospital and I had to see someone at the hospital because of giving birth and I was not able to control myself (Khalida, 42 years old).

Options for treating urinary incontinence include lifestyle changes, behavioral techniques, medications and devices and surgery. However, the first two techniques are considered first, however, the third is considered if the first two techniques

the type of incontinence, how problematic it is, and the impact of leaking urine on daily life.

All those who had accessed continence services had all been initially referred to the physiotherapist, nurse specialist and if needed the urologist and uro-gynaecologist. The use of these services will be discussed as follows.

Nurse specialist

The nurse specialist mainly carried out the initial assessment. This included taking a thorough history, which included questions relating to medication, bowel habits, functional status, sexual dysfunction and quality of life.

Tests that had been carried out on participants included x-rays and ultrasound scans, and urodynamic testing, which focus on the bladder's ability to empty steadily and completely (Abrams et al 2005). A diary of the fluid intake, output and leakage is another management strategy that participants had to complete in the initial assessment stage:

'The nurse first did a test she put water inside me and I have a diary too. I have to write down how many times and how much I leak urine. The nurse told me I can have an operation if it doesn't work. These tablets are for this problem [UI] the nurse gave them to me [...] yes I take them, but they don't help, that is why the nurse gave me pads too' (Tayiba, 63 years old).

Participants who had seen the nurse specialist²⁰ all felt she was generally a 'nice woman', and approachable. Satisfaction about the service received was also related to the fact that those who had sought help now received free sanitary wear, which previously they had to pay for. This has reduced the financial burden that many felt:

'At least now I don't buy my own pads like I did before you know you get them from Tesco. Now she gives them to me' (Zarina, 54 years old).

Physiotherapist

The role of the physiotherapist in continence care is to promote pelvic floor exercises. These exercises are known to strengthen the urinary sphincter and pelvic floor

²⁰ Within the uro-dynamic department there is one nurse specialist who the participants consulted with. I did not have a role to play in these consultations, but was informed whether the patients met the inclusion criteria.

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muscles (DoH 2000). All fourteen participants had consulted with the physiotherapist on several occasions. These sessions included a group session where participants were informed about the aetiology of urinary incontinence. Individual consultations then commenced to train the women in effective pelvic floor exercises.

Participants that had accessed this service were generally unsatisfied, and felt the exercises were not helping with their condition.

'She is not doing anything for me, keeps saying do more exercises, but this is not helping' (Nazia, 54 years old)

For such reasons many of the participants did not carry out the exercises, only one participant felt an improvement in her incontinence.

Communication was another issue, out of 14 participants who had sought help, 12 were accompanied by a female family member.

I have to take my daughter in law with me because sometimes I don't understand what they say...I can sometimes understand little bits but not all, I don't speak English so it makes it hard you know' (Tayiba, 63 years old)

Specialist consultants

If the nurse specialist or the physiotherapist felt that non-surgical treatment options had failed they referred patients to an urologist or an uro-gynaecologist. Out of the 14 participants, five had seen the consultant, and two of these participants went on to have a surgical procedure. Common surgical procedures include: artificial urinary sphincter, bulking material injections, sacral nerve stimulator, sling procedure and the bladder neck suspension (DoH 2000). These two participants were unaware of the type of surgical procedure they had undergone:

'Yes, I know him [consultant urogynaecologist] he is very nice. When I met him the last time he told me that if I have operation because I have very bad urine, sometimes 15 to 20 minutes I want to go to the toilet again. He said if you are going to do operation then might be it is going worse, because you don't know. He was very good as well, and I went to see him 3 to 4 times as well. He ... what do they call it (pause) he burnt my womb neck, ok, after that I was fine. Then again, I feel this as well. After that I went to see X [consultant], they said it was ok, but that time I feel pain passing water and walking and things, but after that [...] operation I was fine, only happens sometimes now, not like before' (Nusrat, 54 years old).

Communication caused a delay in treatment being provided. One participant, Sofia, stated that due to not having any female relatives who could communicate in English, her treatment was delayed:

'I have been seeing X [consultant] for a very long time now. This time I went, he said I can have an operation, but he wanted someone there who could speak Urdu and tell me things. My next appointment is in January and he told me someone who can speak Urdu would be there. X [consultant] gave me some tablets but I have not been taking them for three days now [...] because I do not think they are doing anything for me' (Sofia, 37 years old).

Out of the 14 participants, only two participants actually continued with their treatment regime, and reported an improvement.

'They don't work'

Generally, participants who had accessed continence services felt their health had not improved. Participants who had had both surgical and non-surgical procedures held these views. Thirteen were not satisfied with the behavioural treatments. Some felt that, due to the busy nature of their lifestyle, these exercises were impossible to carry out. Others stated they did not complete the exercises as they wanted other forms of treatment:

'No not at all it is still the same, they did tell me if this doesn't work than I will get a operation but when will that be when I die ... how long are you suppose to wait for help' (Hameeda, 46 years old).

This participant elaborated further, by stating *'if by the end of this year she was not getting her operation she would travel to Pakistan and pay for the treatment'*.

Another participant did not feel any satisfaction after a 'Tension free Vaginal Tape' (TVT) operation. For Farhat the operation did not show any improvement in her condition:

'It is still the same. I still wear pads all the time [...] no not at all, it is still the same as before. X [consultant] told me to lose weight before he can do another operation. So I am trying but the weight is not coming off' (Farhat, 46 years old).

Farhat further stated that she was unable to complete any exercises due to UI. For Farhat any sudden movement or movement that forced her to place pressure on her abdomen such as walking would make her leak:

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Communication caused a delay in treatment being provided. One participant, Soha,

'I did try to exercise; you know walking up and down this street. The thing is I live on top of this hill, not bad when walking down but when I have to come back up I leak urine ... look here I have to sit on this big pad... my doctor has put me on tablets that will help with the weight, but I don't think they are helping' (Farhat, 46 years old).

Non-compliance to non-surgical procedures such as pelvic floor exercise and oral medication was common. Inevitably, these measures did not improve the women's symptoms of urinary incontinence. The main reason given for the lack of compliance was due to many of the women wanting surgical procedures. Due to this, many refused to carry out management strategies identified by the nurse specialist or the physiotherapist:

'I do not do the exercises, I want to have tablets or operation not this exercises this has been going on for too long now' (Nazia, 54 years old).

Some participants also reported that they did not comply with taking prescribed medication as a result of perceived side-effects. However, none of these participants had informed their health care professionals that they had stopped oral medication and exercises:

'X [nurse specialist] said I have to try tablets first and then if does not work an operation ... yes, that is what I want. I have not taken those [tablets] for 10 days now, they make me ill ... just dizzy all the time [...] No the nurse was at the hospital, here is the letter. I cannot say her name properly ... no, do you think I should tell her that I am not taking them anymore...I will (shouts out for daughter in law); we have to ring this nurse. Can't you tell her when you see her at the hospital it will be easier that way I think' (Ghazala, 76 years old).

Only two participants felt their condition had improved, and that treatment had a positive impact on their lives:

'I do what are they called pelvic floor exercises, which X [physiotherapist] has shown me how to do. She examined me and said I just need to tighten my muscles. This is the second time I have seen her now. When I went a couple of days ago I asked her to tell me if I was doing them right, she again examined me and I had to do the exercises and she said I was doing them right. So something must be working. Yes honest they [exercises] really are helping. I feel much better then what I did before. Most of the time I do do the exercises, I am also on maternity leave now, so while Sana is sleeping I can do them. I want to enjoy being a mum now. I had PND (post natal depression) after Sana you see so I was very down but now I am much better and feel I should get my life back together' (Ameena, 27 years old).

'I went to see X [consultant], he looked inside and said they have gone now, might be for that I do not have this problem now [...] when I pray namaz my water is not

coming, but after that when they have disappeared I feel better. Yes, not 100% better but better' (Nusrat, 54 years old).

Non-compliance was also common in exercising for other medical conditions, especially where UI complicated these exercises:

'I was told to take walks and things, but I cannot when I do I need to take a supply of pads with me ... I just tend to sit at home, I also have arthritis too it's hard to walk' (Farhat, 46 years old).

The next and final theme indicates that even when conditions of leaking urine had improved considerably as a consequence of formal help-seeking, some women felt guilty about going against what they perceived as religious prohibitions. This is very important in terms of their likelihood of seeking more help in the future, and, possibly also influences the kinds of messages that are disseminated to family and friends in similar situations.

'I have done wrong'

As the physiotherapist and the nurse specialist were both females there were no perceived religious restrictions placed on these women whilst under their care. However, both the urologist and the uro-gynaecologist were male, and this did feature in the narratives of participants who did not show any improvement through pelvic floor exercises or oral medication and who were referred to these consultants, usually for surgical procedures. Examination placed many of these participants in awkward circumstances. Many stated that throughout the care pathway, they had requested to see a female consultant, but at the time none were available.

'Then I had to see a man, X [consultant], I felt shy but I was told by my link worker, it doesn't matter whether it is male or female as long as they do a good job' (Farhat, 46 years old).

'I told X [physiotherapist] I want to see a woman but she [physiotherapist] has said if I want to see a lady doctor I will have to go to Burnley hospital, I am not going to Burnley. I wouldn't see X [consultant urologist/male] because he has to examine me, is there no woman doctor at the hospital that can do this job. Child it is wrong for us Muslim to be checked by a man' (Nazia, 54 years old).

Those who had seen the specialist consultants stated they had 'done wrong' by their religion, and would sincerely ask God for forgiveness. Many participants felt let down by the health care staff as they were informed that female doctors would be available. Exposing themselves to male doctors for these women was a sin, a sin that may not be forgiven.

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This can only be explained through the perceptions the participants had of the health care system and feeling let down by health care professionals. The National Health Service takes into account the needs of 'all' accessing services, and has identified that patients' rights to treatment should be the main priority. However in practice this is not always possible and some patients may, like the women in this study, have religious or cultural beliefs that could not be catered for. This then becomes a collision of perceptions of what is right and what is permitted.

'Islam does not stop any woman seeking health care but when I had to be examined by my doctor I did think God is going to punish me. But if no woman doctor is available then you have to go to a man. You see I think here different countries matter I mean in Pakistan we had woman Muslim doctors who did examinations but here it is not the case (pause) so if you need health care than you will have to go to a man doctor' (Khalida, 52 years old).

'Yes, but I had no choice, I can urinate everywhere or show a man. I know I must be doing wrong but if he is helping me than am I ... it does say in our religion that we can see a lady doctor but not from a male ... you see that is what I think and have been told, but what do you do if you are in need' (Sofia, 37 years old).

Summary

In this chapter, I have considered aspects of service provision experienced by those participants who had accessed continence care. Satisfaction with their overall health care provision was generally poor as many felt their symptoms did not improve at all. Non-compliance was also very common. Women refused to complete a treatment plan such as pelvic floor exercise and oral medication, which many felt was inappropriate as they had already tried self-management, sometimes for years, and they felt that now the only way their symptoms could improve was through surgical procedures.

In the previous chapter it was noted that many participants would in principle refuse health care where only a male health care professional was available. In this chapter, however, we have seen that due to their circumstances, many would seek help and then ask for forgiveness from their God, as no other options were available. This only became apparent as the interviews progressed. Many of the participant especially the older women, had stated that exposing oneself to a male was totally against their religious beliefs, however the inability to worship their God was a much bigger sin. Therefore to maintain a balance participants that had sought help had been examined by a male consultant. Whilst these participants discussed this issue a

This can only be explained through the perceptions the participants had of the health care system and feeling let down by health care professionals. The National Health Service takes into account the needs of 'all' accessing services, and has identified that patients' rights to treatment should be the main priority. However in practice this is not always possible and some patients may, like the women in this study, have religious or cultural beliefs that could not be catered for. This then becomes a collision of perceptions of what is right and what is permitted.

Islam does not stop any woman seeking health care but when I had to be examined by my doctor I did think God is going to punish me. But if no woman doctor is available then you have to go to a man. You see I think there different countries matter I mean in Pakistan we had woman Muslim doctors who did examinations but here it is not the case (parae) so if you need health care then you will have to go to a man doctor (Iqbalida, 52 years old).

Yes, but I had no choice, I can urinate everywhere or show a man. I know I must be doing wrong but it is helping me then and I ... it does say in our religion that we can see a lady doctor but not from a male ... you see that is what I think and have been told, but what do you do if you are in need (Goffe, 57 years old).

Summary

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sense of shame was noted: none of these women maintained eye contact, for others disclosing such personal matter caused them upset.

In the next chapter, I will bring together the findings in a synthesis of the data, and provide a theoretical discussion of why the participants' beliefs, practices and behaviours took place the way they did. I will refer to the literature review chapters to support my findings in relation to UI, religion and help-seeking behaviour.

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Chapter 12

Bringing it all together – synthesis

Introduction

The previous chapters have considered the thoughts, beliefs and practices of the 41 participants in this study through their own narratives of urinary incontinence, cultural influences, and the impact of Islam on their lives.

An understanding of what these women were describing required an acknowledgement that their culture, which was based on Islam and Islamic teaching, was essential for them. This filtered through their thinking, their behaviour, their beliefs and practices. It influenced every aspect of their lives, thus contributing to their understanding of life and their interactions with others.

Three overarching themes

Through the process of engaging with the data, it became clear that the women were describing a 'balancing act'. This included their perceived role as Muslim women, their family, continuing religious and cultural practices, and their health, in a country in which most of them felt alienated. Many of the participants managed multiple roles. The impact of this meant their health was sometimes overlooked. Their lives revolved around their families, where Islam became the centre of all acts and practices.

The concept titled the 'balancing act' examines these women's roles in their family, balanced with how they managed their health.

The three elements in the balancing act cannot be untangled and described as separate entities. The meaning of UI for these women was a complex 'whole', where the 'parts' that constructed the 'whole' were the family, religion and culture, health, illness and wellbeing. In Gadamer's words, this process is understood as the *'hermeneutic circle; - a contextually fulfilled circle which joins the [conversationalists] into unity with a processual whole'* (Gadamer 1987; pg 87). Therefore the process of understanding the findings of this research entailed a constant movement from the 'whole' to the 'parts'.

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Family, religion, and culture

The data confirmed that family was the backbone for these participants. Even though many were adapting to the 'nuclear' family, the concept of the extended family remained more influential. This related to a sense of belonging and 'wantedness'. It seemed to be intensified by a feeling of rejection by the British society, due to religious belief. This inevitably forced many back to their families as a point of reference. For such reasons many of the women in this study referred to themselves or described themselves primarily as Muslim. Islam became their identity, a lens that had become so powerful that, through their narratives, a strong sense of 'protection or rejection' was evident. Khalsoom, a British born Muslim woman, describes of her identity as follows:

'Myself (pause) um Muslim Indian I think, I am British but I suppose no matter how much you want to fit in the first thing people see is your colour. I think it is harder for us who are born in the UK anyway, no matter how much we try and fit in, we will never be them. So why not say you are Muslims' (Khalsoom, 26 years).

Acceptance became a major issue for all participants. Possibly paradoxically, it was more difficult for those born in the UK, who felt that they were 'living a double life', by adapting Western views while trying to maintain their religion and culture in a process that, itself, had become a balancing act.

Participants made meaning out of this situation by maintaining practices which were usually reinforced through culture and family, and that were originally embedded with their religion. Continuing with such practices allowed many to feel 'part' of a group, permitting a sense of belonging in a country that was alien to them, a country that, they felt, had not welcomed them due to their religious beliefs. Many resided in areas that were predominantly 'Asian' or 'Muslim' – where the majority had similar views, continued similar practices and had the possibility to keep their religion alive. Their identity, their attire, their speech and their own environments appeared to be very overtly Islamic. Ahmed (1996) refers to this as a '*biraderi*', a system that exists within the South Asian communities offering an important source of identity and support, based on reciprocal relationships of moral, social and financial obligations (pg 56). Tayiba a 63-year-old Pakistani woman describes this concept of *biraderi*:

'This area here is full of Muslim people. We are all the same, it is nice especially when there are weddings and things ... It is nice like in ramazan when we all get together its nice... I miss home in Pakistan and I would like to go back there for good one day ... It is nice, I know this is not our country, but the people living around here

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are all the same, they are all Muslims. We all look out for one another, and there is always someone that you can talk to' (Tayiba 63 years).

Many participants did not perceive any problems due to residing in Asian areas. However in my interpretation negative aspects do appear. Many of the participants were non-English speaking. They had never had the need to learn English, as the people they would communicate with regularly all spoke the common language of Urdu. This included the GPs, the local shopkeepers and their neighbours. Referring back to Ghazala's words provides a reminder of some of the pressures many felt when arriving into the UK, and why learning to communicate in English was not a necessity:

'Um when I came here, my husband was already here. I came with my three children. It was hard at that time, because you do not know anyone or anything. I stayed in the house and my husband worked. That was my life, I hear my children speaking English, and know some words but not a lot' (Ghazala, 76 years old).

Secondly, and most importantly, women talked about the problems they faced when arriving into the UK from countries such as India or Pakistan, where the way of living was different than in the UK. They feared not only rejection by the British society, but also rejection in the communities they lived in if they transgressed community rules. This appeared to be complicated by a lack of access for those outside the community, so that they had limited opportunity to gain an understanding of the views, values and practices of the Muslim communities. At the same time as closing themselves away from British people, some of the participants felt 'judged' by them. Many had therefore appeared to have created boundaries between themselves and the wider British society. Consequently, some seemed to have alienated themselves from seeking health care from professionals. Specifically, some women believed that British professionals would not understand why they behaved and acted in certain ways.

'Big problem they do not understand how we live sometimes look at you funny (pause) now worse people think all Muslim is [are] terrorist. Not all if you wear scarf you terrorist ... They do things we don't do and we do things they don't do this is a problem people don't understand each other. I have lived in this country for very long time I have seen others look at Asians, that is why I have Asian doctor who understands me and the way I live' (Sobia, 58 years).

An attempt to understand this process required a closer look at the socialisation process of the Muslim culture. Since early childhood, gender roles are clearly delineated. A female is socialised first in preparation for her role as homemaker and mother. The male, on the other hand, is prepared to be the breadwinner. It follows,

therefore, that a male's education is favoured over that of the female. Despite this cultural practice, religiously in Islam, women are free to work outside the house and hold any profession in Islam as long as the sanctity of the family remains intact and a women's honour is not compromised (Al-Musnad 1996, pg 313). Family obligations within the South Asian context are complex, especially where Muslim women are concerned. The position of wives and daughters-in-law is interesting. On the one hand, the participants' narratives speak of feeling trapped by the rules that were placed on them through their husbands, mothers-in-law and the wider society. These were designed to portray the 'traditional Asian woman image', where women had limited say or powers. However, when these women become older they automatically became the head of the household. In this role, they determined what should be done and how the next generation should live their lives. This process of continued practices and traditions that had been once forced upon them into the next generations. Ahmed (1996) stated that an individual's position in the South Asian family carries with it a complex of duties, rights, obligations and expectations (pg 57). Therefore, it is highly important for Asian women to continue culturally driven practices if they are to maintain family honour, protect their moral reputation, and therefore to engender a sense of acceptance.

Despite the words of the Quran and the Shariah law advocating equality in both sexes cultural superiority of the male gender is enforced, and many women live under the mercy of man-made laws (Hamid, 1997). The following verse is taken from the Quran, in which Allah strongly recommends equality:

'O men fear women if you know what is good for you...'

In a much broader sense this means resisting the temptation to oppress, and not dictate the lives of wives, mothers, daughters or sisters. However, not all the participants in this study suffered at the hands of their husbands or mother in laws. There were clear differences which appeared to be related to educational status, ethnic background (Pakistani, Indian, British) and reinforcement of cultural practices, which were referred to as religious. Ahmed (1992) refers to this as '*fundamentally different Islam's*' which arises through different interpretations and readings of the same Islamic texts. If such differences within the same religion have become commonplace, then it becomes '*imperative to challenge the authoritarian readings of Islam that are profoundly affecting many Muslim women across the world*' (Barlas, 2002 pg 2).

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Even though many participants in this study directly experienced oppression by the husbands, none questioned their legitimacy. They did not appear to be aware of their religious rights as Muslim women, and they had not read the Quran's teachings. 'Acceptable' and 'non-acceptable' behaviour was interpreted through what women believed the men in their communities required of them. The participants perceived their roles as Muslim women to be child-bearers, carers and nurturers. Employment and education were not the norm. This set of norms provided reinforcement for the stereotype of 'traditional Asian woman' (Naidoo and Davies 1988). Transgressing these norms by taking up employment and wearing Western clothing took on both religious and cultural overtones: it was seen as un-Islamic as well as un-Asian. Some participants insisted that those who took up such practices could not be regarded as Muslims:

'I have never worked because a Muslim woman should not work and plus my dad didn't want his girls to work, and nor did my husband... Do you work? [Question to the researcher ...yes] It is because you are India, Pakistani girls should not work. Girls don't need to go and find job that is for men to do' (Sofia, 37 years).

The meaning of illness

The counterbalance in the scales is the meaning of illness. Many definitions of health exist. What illness or being well is for an individual is a subjective interpretation, viewed from that individual's perspective. 'Health' and 'well-being' for the 41 women in this study occurred through a complex interplay between personal experiences and cultural factors, including language and religion. Generally, 'health' referred to the absence of any illness or regular taking of medication. Many women in this study therefore defined their health as poor, as many took regular medication. Health was also viewed through the Islamic perspective. Many participants made statements such as: *'good and bad health is from Allah, who was the only one that would send them a cure'*. For example, as Tanzeela describes:

'If you have an illness or something it is from God but God has given us the brain to work out the solution for each problem or illness. Ok sometimes there may not be a cure but Allah will not let you suffer' (Tanzeela, 37 years).

From their religious perspective, Muslim women's recovery from any condition or deterioration was *ONLY* in the hands of their God, because God meant it to be that way. It was also recognised by some that seeking health care was 'the way' that God had shown them. God was the one that provides people with the knowledge to

become doctors. Ultimately, everything was in the hands of God. According to Khayat and Haytham (1999), health within the Islamic framework is described as a *'state of complete physical, psychological, social and spiritual well-being'*. Except for one important area, this definition is not different from the WHO (1994) definition of health as *'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'*. The additional element for Khayat and Haytham was spiritual health, which they considered to be the most important aspect. As the prophet Muhammed (saw) stated *'Allah does not look to your bodies or your forms, but rather He looks to your hearts'* (Sheikh and Gatrad, 2000, pg 30). For this reason many Muslim communities discard 'depression' as an illness, as it is seen to be related to a lack of faith (Fonte, 2005).

Cultural norms are not easy to change. Christakis and Panner (1991) and Christakis (1992) report that culturally shared values do not change rapidly. This was supported in this study as similar views emerged between first and second generations. With advancing age, it was perhaps not surprising to hear older South Asian Muslim women describe their health as 'not good'. It was worrying that many younger participants also described their health this way.

Health and well-being are understood to be the greatest blessings to have been given to people and for which they are accountable to Allah (Khayat and Haytham, 1999). This implied that care should be taken to rid the body of illness and disease as much as possible. However, 'illness' and 'disease' were not related to leaking urine by many participants. There was a belief that UI was a normal part of ageing and childbirth, as opposed to a disease. A recent study by Doshani et al (2007) found South Asian Indian women considered UI to be part of the ageing process therefore symptoms became normalised. This was reinforced by health care professionals, as some of those who had sought help reported that the staff they saw implied that UI was a normal consequence of giving birth, also found by Doshani et al (2007).

Many responded to this by self-managing. 'Real' illnesses, for these women, were those where medication was prescribed. Some participants were commenced on oxybutynin (prescribed medication for urinary incontinence – antispasmodic drug) although they believed it was to clear urinary tract infections and not for incontinence. Therefore UI was interpreted as a 'condition' that was manageable, and not a significant or a real illness.

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The balancing act

Through the narratives, it became apparent that the way these women managed their condition(s) and their life was through the influences of their religion, culture, their family, and observing others. This allowed these women to normalise their lives through one of the following responses: self-managing their condition and becoming lay experts; taking on the 'sickness role' (usually related to the older women); or seeking professional help once this could be interpreted as sanctioned religiously.

'Lay experts' coping and self-managing

For those participants who had not sought help, and those who were at the early stages of treatment, self-management was the best and the only option. In Doshani et al's (2007) study participants also developed self-management strategies due to a belief that little can be done to achieve continence status. However, referring back to this study, these women were certain that religion restricted them from seeking health care due to the requirement for intimate examination, and the need for their husbands to be informed, so they could accompany them to consultations. To avoid such situations, many managed their condition themselves.

The meaning women ascribed to self-management strategies was contextual and involved finding ways to live their daily lives optimally, by creating order from the disruption and disorder imposed onto them. Learning such self-management strategies was not without further complications. For example, restricting fluid intake decreased the amount of urine leaked, and maintained an apparent normality. However restricting fluid intake can increase the likelihood of developing recurrent UTI's, and increasing the frequency of urine leakage (Bates 2000).

Despite the problems of self-management, some of those in the study revealed that self-management was an active process of learning, and exploring the boundaries created by leaking urine. Consequently, self-taught behaviour allowed many participants to take on the 'lay expert' role, by managing and balancing their condition and their health. This phenomenon was discussed in more depth in chapter 8 ('It is the norm' section pg 165).

'Sick role'

'Being sick' is not simply a 'state of fact' or 'condition', it is a specifically patterned social role (Parsons 1951 pg 436-7). According to Parson (1951, 1975), older Muslim women tend to take on an overt sick role when they experience 'real' illness (as

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defined above). Elderly South Asian Muslim women in this study had taken on such a role, and expected others to care for them. Within the Islamic manner of life, caring for the elders of the family is also seen as a way of pleasing Allah. Therefore the older Muslim women in the study became accustomed to play the sick role. This role was adapted as they felt they had reached the end of their lives, by stating *'they had done their bit'*. Within the religious perspective these women felt that this position was a legitimate one to adapt to, and one that was encouraged through Islam. This is discussed in chapter 7 'religion as a referential framework'.

External help-seeking was also discouraged by the view of urinary incontinence as a normal part of ageing.

Help-seeking

Participants only started the process of seeking professional help when they felt their symptoms to be unmanageable. The more severe the leakages the more likely these women were to seek help. Severity of the leakage was judged both by how much it restricted their daily activities, and (most importantly) by how much of a barrier it created between themselves and their God. Leaking urine whether involuntarily or voluntarily whilst under ablution is regarded as 'filth' in the Islamic view. For many participants, not being able to worship their God as they were impure due to leakage of urine was seen as a greater sin than seeking health care from a male doctor. Therefore, those who had sought help had broken away from the cultural taboo on intimate health care from men to better their health, and, more importantly, had regained the ability to worship their God. It is worth noting that when such acts were carried out many of the participants referred to the process as a 'sign' from their God, or a spiritual healer, that help should be sought, placing the responsibility on someone else.

However, this decision was not without personal costs. Some women who had consulted with male doctors felt they had caused a grave sin, by exposing themselves in front of strange men. However these women did state that the ability to perform prayers without leaking allowed them to worship once again, further allowing them to seek for forgiveness.

In Doshani et al's (2007) study examination by male GPs was also an issue however women in that study believed such acts to be embarrassing and not religiously based.

Applying a Theoretical interpretation

Interpretations of health and illness, and the nature of help-seeking behaviour have been widely studied (Cameron et al 1995; Koziol-McLain et al 2000; Shaw 2001; Greenhalgh and Wessely 2004). It appears that whether people perceive their health as good or bad predicts help-seeking or coping (Ong et al 1995; Yankeelov et al 1995). The literature review chapter section II draws attention towards some of the models that have been used to predict such behaviour (see pages 46-52), these include the locus of control (Rotter, 1954); social cognition model (Bandura, 1971); health belief model (1974); theory of reasoned action (Ajzen and Fishbein, 1980) and theory of planned behaviour (Ajzen and Madden, 1986).

A number of critiques have been made of such models. For example, the health locus of control has been criticised as it fails to pay attention to the value people place on their health (Wallston 1992). Rotter (1966) has argued that the health locus of control beliefs should only predict health behaviour when health is highly valued by individuals. This suggests that South Asian Muslim women in this study in Rotter's view would suggest that health is not valued in relation to leaking urine, as urinary incontinence was not a classified or a significant condition. However, it appears that South Asian Muslim women in this study had a higher external locus of control than internal. They felt their God controlled and predicted their life and events that occurred. This meant that all health/illness issues were received with open arms, as many felt it was a way of God testing their patience and a way of cleansing the soul of sin. Health was of great value to these women, however not in relation to leaking urine, which was the aim of this study. For these reasons, I disregarded this model, as it appears to be advocating that only those people who value a specific interpretation of 'health' can be tested against this model.

The health belief model (Becker, 1974) is another model that is used extensively I rejected this model due to a number of limitations. Chapman (1984) suggests there is a lack of consistency in testing and using the model, especially in the way constructs are utilised or excluded. For example the additional concept of 'cues' to action that triggers behaviour change (Becker and Maiman, 1975) has been problematic and excluded (Harrison, 1992). Poss (2001) states cues can be diverse in nature, may occur in a brief manner, and the individuals may or may not consciously remember events that triggered the initial action. This model does however indicate that the likelihood of people taking up screening relates to an individual's perception of the

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likelihood that they will *suffer* from the condition, which in turn instigates health-promoting activities. Many of the participants did not feel leaking urine was bothersome, as participants developed self-management strategies that allowed them to manage their condition independently. Even when participants sought help, the strategies that they themselves had adapted were reinforced by continence advisors, which only led to non-compliance to treatment, and increased psychological distress. This is one major criticism of this model, as stated by Ogden (2000). Emotional factors are not considered within the HBM, as they are seen to be socially disruptive factors. Emotional/psychological factors were probably more important to these women as they had broken away from religiously and cultural taught behaviour to seek help. Other factors such as demographic variables, personality factors, social support, or previous health experiences, play a role in influencing behaviour, but again they are not an explicit part of the model (Poss 2001).

Similar criticisms have been found with the other three models discussed in chapter two, literature review II. For example, the theory of reasoned action does not include other variables such as demographic characteristics and personality traits.

Although these models are extensively used, and they are very successful in many studies (Kirscht, 1988) they do not seem to have the theoretical basis to explain what is happening with the women in this study, as these models are specific to illness, and women in this study did not generally see themselves as being ill in relation to UI. These commonly used models emphasise stable health beliefs, are provider focused, and do not adequately acknowledge the patients' perspectives (Kleinman, 1980; Heurtin-Roberts and Reisin, 1992). For this reason I turned to Antonovsky's 'salutogenesis' theory and Young's 'five fold medical model'. Antonovsky (1979) suggest that, instead of concentrating on and 'illness', the focus should be turned towards how people manage to stay 'well' under episodes of illness or sickness. The attention is removed from viewing a person as a 'illness' or 'condition' towards a much more holistic picture, taking into consideration the concept of religion, rituals and culture that can impact on the way people cope with episodes of stress. Young's (1981) theory is similar to Antonovsky's. However the central concept of this theory is 'dialogue' and takes into consideration that 'emotional' and 'expressive' factors are fundamental to the understanding that individuals have of their conditions.

Both these theories are patient focused and are catered for each person as a unique individual, rather than as a 'condition'. Therefore in order to explain my data, I draw

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Both these theories are patient focused and are catered for each person as a unique individual, rather than as a 'condition'. Therefore in order to explain my data, I draw

upon Antonovsky's model of 'Salutogenesis' (Antonovsky, 1979) and on the critique of the 'Rational Man' position taken by Young (1981), to aid understanding and interpretation. Antonovsky does not look specifically at illness but towards 'wellness' and towards understanding factors that directly impact on individual cognitions. Young critiques simplistic linear explanatory models of sickness. By combining these theories it is easier to appreciate the participants' contextually situated logical 'way of seeing' things in their life that they draw upon to understand the nature of illness and how they may address it.

'Salutogenesis'

Aaron Antonovsky, a medical sociologist, focused on adults who remained physically and mentally healthy under conditions of severe stress (Antonovsky, 1979, pg 8). Antonovsky describes this as a 'question of salutogenesis', the origins of health and 'good beginning'. He hypothesised that this concept is at the opposite end of the medical term 'pathogenic' which has its origins in discovering the nature and cause of disease (Antonovsky 1979). The four main conceptual elements of the salutogenic model are:

- a) *Stressors*: that inhibits the individual's psychological equilibrium and present demands to which there are no readily available responses (pg 72). Antonovsky (1979) claims that human existence is characterised by moderate to severe levels of stressors, which then trigger ways in which people can cope or manage.
- b) *Tension, tension management*: is the response to a stressor and is both an emotional and physiological phenomenon (Horsburgh et al 1998). What Antonovsky (1987) suggests is tensions are 'the recognition in the brain that some need one has is unfulfilled, that a demand on one has to be met, that one must do something if one is to realise a goal' (1987, pg 96). The ability to manage tension and avoid or manage stress is influenced by factors Antonovsky describes as 'general resistance resources'.
- c) *Generalised resistance resources (GRRs)*: 'any characteristic of the person, group, or environment that can facilitate effective tension management', which can facilitate avoiding or combating a wide range of stressors (Antonovsky 1979, pg 99). Examples of GRRs are money, shelter and food, intelligence and knowledge, social support, rituals and religion, all of which contribute to the development of 'sense of coherence' which is the central concept of the salutogenesis model.

- d) *Sense of coherence (SOC)*: Antonovsky (1979) defined the Sense of Coherence as an individual's pervasive, enduring confidence in the predictability and manageability of his environment. The SOC is 'a crucial element in the basic personality structure of an individual and in the ambiance of a subculture, culture, or historical period' (pg 124). According to Antonovsky, SOC is developed throughout childhood, is formed but likely to change during adolescent years, and probably reaches its final, concrete form by the age of 30. The more the experiences of stress and tension are confronted and overcome by the individual the more likely according to Antonovsky the individual will view the world as coherent and predictable.

To understand the concept of salutogenesis, according to Antonovsky, one must primarily understand the sense of coherence (SOC) concept which is defined as follows:

'A global orientation that expresses the extent to which one has a pervasive, enduring through dynamic feeling of confidence a) that one's internal and external environments are structured, predictable, and explicable [comprehensibility].

b) the resources are available to one to meet the demands posed by these stimuli [manageability] and c) those demands are challenges, worthy of investment and engagement' [meaningfulness] (Antonovsky, 1987; pg 17).

Although the three components of the SOC are viewed as highly related to one another, there is clearly an order of importance. 'Meaningfulness' within the salutogenic model is seen as the concept that motivates an individual who wishes to cope. It is the central component. Those with a strong SOC perceive stressors or life events as comprehensible, making sense cognitively, and under the control of oneself or legitimate others (Antonovsky, 1996). Comprehensibility is viewed as second in importance. Manageability is largely dependent on how one perceives and understands stress. Antonovsky stresses that although there is an importance of order in these three concepts that all three were as important as each other in distinguishing a strong SOC (Antonovsky, 1987, pg 22).

This theory assumes that progress on the three dimensions, comprehensibility, manageability and meaningfulness, leads to greater SOC, and therefore improved coping with extreme cases. People with a high SOC do not appear to perceive stressful events as threatening or uncontrollable (Antonovsky, 1979). Confidence in the predictability and manageability of the environment is one of the qualities of SOC.

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A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of coherence a) that one's internal and external environments are structured, predictable, and explicable (comprehensibility), b) the resources are available to one to meet the demands posed by these stimuli (manageability), and c) these demands are challenges, worthy of investment and engagement (meaningfulness) (Antonovsky, 1987, pg. 17).

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The person with a strong sense of coherence who experiences stressors, Antonovsky hypothesised, is capable of clarifying and structuring the nature of the stressors, believes that the appropriate resources are available and can be mobilised to deal successfully with the challenges, and is motivated to deal with it (Antonovsky, 1987, pg 21). Such an orientation in life, Antonovsky offers, allows the selection of appropriate coping strategies and provides a solid base for maintenance and strengthening of health and well-being.

'The five-fold medical knowledge'

In 1981 Allan Young published a seminal text: *'when Rational Men Fall sick: an inquiry into some assumptions made by medical anthropologists'*. Young states that explanatory models are tailored to fit the Rational Man rather than real people and are centred on the four basic assumptions of language, knowledge, reasoning and causality (Young, 1981). What Young suggests is that through this model a person's emotional and expressive responses are not considered and are sometimes overlooked as they are seen as socially disruptive forces, which require control (Young, 1981). Personal thoughts about sickness can stimulate an increase in emotional distress, and this prolonged emotional state can further effect a person's understanding of the condition. What Young suggests is that taking account of expressive response and emotional response such as facial expressions, posture, and the emotional tone of statements, is a way of translating through non-verbal cues how the individual may be feeling towards the given condition. These are as important as verbal cues.

Allowing patients to express the logical rationale of their assumptions about the presenting condition, according to Young, requires paying attention to the five-fold model he proposes, which has its base in the theory that those presenting with a condition understand in their own terms why and how illness occurred (Toombs 1993, pg 47). Young suggests that *'people use a kind of knowledge to organise their medical experiences and perceptions'* (Young 1981) as follows:

1. *Theoretical knowledge*: a process of sickness and healing that the sufferer organises into categories.
2. *Empirical knowledge*: that takes account, albeit selectively, of the particularities of things and experience – objects, events, and experiences that he has observed or that have related to him.

The person with a strong sense of coherence who experiences stressors, is capable of identifying and structuring the nature of the stressors, believes that the appropriate resources are available and can be mobilised to deal successfully with the challenges, and is motivated to deal with it (Antonovsky, 1987, pg 21). Such an orientation in life, Antonovsky offers, allows the selection of appropriate coping strategies and provides a solid base for maintenance and strengthening of health and well-being.

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1. Theoretical knowledge: a process of science and reasoning that the sufferer organises into categories.
2. Empirical knowledge: that takes account, albeit selectively, of the particularities of things and experience - objects, events, and experiences that he has observed or that have related to him.

3. *Rationalised knowledge*: in which he conceptualises objects, events and experiences in psychologically satisfying ways (by organising medical events into coherent narrative). Making them ontologically consistent with his beliefs about the nature of the material world and existentially coherent with his beliefs and feeling about his and other people's essential nature, previous life experiences, fate etc.
4. *Inter-subjective knowledge*: in which he conceptualises objects, events, and experiences in ways and words which he believes will make them intelligible to the people with whom he wants to communicate.
5. *Negotiated knowledge*: the meaning of objects, events, and experiences, in interaction with other people (Young, 1981).

Considering all five of the medical knowledge concepts allows a grasp of the whole picture of the individual and not just disease specific information. Young's theory is focused on the importance of language and what people assign to illness, health, and well-being, with a focus on how beliefs are used to obtain treatment during actual sickness episodes (Fabrega, 1975). Young states that it would be impossible to understand what people say and do if we did not take into account their strong rational and logical tendencies. In other words, we would need to understand through this concept the individual's account of how and why sickness occurred, how it ran its course, and what outcomes were reached (Young, 1981). Kleinman (1980) elaborates further by stating that this process provides the information that is required in choosing medical strategies, communication, and recognising distress (pg 71-72).

Summary of theoretical interpretations through the 'five-fold medical knowledge' and 'sense of coherence'

The basis for these explanatory theories may not be the standard biomedical Western view, but this does not make them less valid. Bringing it all together and summarising the theoretical interpretations and the findings from this study leads to the hypothesis that urinary incontinence, health, illness, and well-being for the women in this study can all be constructed through the five-fold model of medical knowledge consisting of *theoretical, empirical, rationalised, inter-subjective and negotiating knowledge* that people use to organise their medical experiences and perceptions (Young 1981). These will now be discussed in light of the findings, and in response to the five assumptions which are then mediated through Antonovsky's

3. Rationalised knowledge: in which a person has been able to transform experiences in psychologically acceptable ways into a coherent narrative, making sense of what has happened, and coming to terms about the nature of the problem, what has happened, and what he or she believes and feeling about his or her situation, and what he or she has experienced, etc.
4. Inter-subjective knowledge: in which a person has been able to transform experiences in ways and words which are acceptable to others, and to the people with whom he or she is interacting.
5. Negotiated knowledge: the meaning of what has happened, and what he or she believes and feeling about his or her situation, and what he or she has experienced, etc.

Considering all five of the medical approaches to the understanding of the picture of the individual and not just seeing it as a single, coherent picture, focused on the importance of language, and the importance of the individual's well-being, with a focus on how beliefs and attitudes can be transformed, and how they address episodes (Young, 1991). Young (1991) argues that the medical approach to understanding what people say and do is not enough. It is not enough to understand rational and logical tendencies in other words, rational and logical tendencies in this concept the individual's account of what has happened, and what he or she believes and feeling about his or her situation, and what he or she has experienced, etc. The medical approach to understanding the picture of the individual and not just seeing it as a single, coherent picture, focused on the importance of language, and the importance of the individual's well-being, with a focus on how beliefs and attitudes can be transformed, and how they address episodes (Young, 1991).

Summary of theoretical approaches to understanding the picture of the individual and not just seeing it as a single, coherent picture, focused on the importance of language, and the importance of the individual's well-being, with a focus on how beliefs and attitudes can be transformed, and how they address episodes (Young, 1991). The basis for these explanatory approaches is the medical approach to understanding the picture of the individual and not just seeing it as a single, coherent picture, focused on the importance of language, and the importance of the individual's well-being, with a focus on how beliefs and attitudes can be transformed, and how they address episodes (Young, 1991). The hypothesis that urinary incontinence is a medical problem, and that it can be treated with medical interventions, is the basis for the medical approach to understanding the picture of the individual and not just seeing it as a single, coherent picture, focused on the importance of language, and the importance of the individual's well-being, with a focus on how beliefs and attitudes can be transformed, and how they address episodes (Young, 1991). These will now be discussed in the context of the five assumptions which are the basis for the medical approach to understanding the picture of the individual and not just seeing it as a single, coherent picture, focused on the importance of language, and the importance of the individual's well-being, with a focus on how beliefs and attitudes can be transformed, and how they address episodes (Young, 1991).

sense of coherence concepts of *meaningfulness, manageability, and comprehensibility*. The understanding of urinary symptoms is based on embodied physiological processes, influenced by socially expected norms. It is only when such norms are violated, and when women cannot effectively balance the family and the illness, that social and psychological consequences arise. It is therefore imperative to understand cultural influences that are embedded within each societal expectation, belief, norm, practice and value.

Theoretical knowledge: real illnesses and not real illnesses

'Incontinence is not a disease but rather a condition with multiple aetiologies, associated factors, and physical, psychological and social consequences' (Palmer 1996).

Illness or disease can be understood as 'something' that invades or 'imbalances' the body's natural being, therefore tipping the health equilibrium balance. As many of the women in the study suffered from what they saw as 'real' illnesses, such as diabetes, asthma, angina and hypertension, investing energy into leaking urine was not a concern. This influenced them to view urinary incontinence as not a significant problem, or not life threatening, making it not a real illness, unless it began to significantly effect their religious observance.

Theoretical knowledge is based on absolute and detailed statements of all possible conditions that can explain a process or behaviour. Understanding what UI meant to these women was to understand their theoretical knowledge about the given condition.

Perceptions of health and illness were also reasoned through a strong religious orientation. Participants talked about how an illness was in the hands of God, therefore putting it down to God's will. For some women their religious faith enabled them to come to terms with the situation and accept it with open hands, or in Antonovsky's terms as meaningful.

The salutogenesis model proposes that a strong sense of religion and spirituality contributes to the SOC by providing ready answers to human events such as death and pain (Antonovsky, 1979). Religion served as a source of support by providing strength and helping these women gain meaning in situations of extreme stress (Graham et al 2001). Higher levels of religious faith and spirituality are associated with more adaptive coping responses, higher resilience to stress, a more optimistic

sense of coherence concepts of meaningfulness, manageability, and comprehensibility. The understanding of urinary symptoms is based on embodied physiological processes, influenced by socially expected norms. It is only when such norms are violated, and when women cannot effectively balance the family and the illness, that social and psychological consequences arise. It is therefore imperative to understand cultural influences that are embedded within each social expectation, belief, norm, practice and value.

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life orientation, greater perceived social support, and lower levels of anxiety (Pargament, 1997).

According to Young (1981) a person uses his historical knowledge of sickness and healing to organise discrete events into classes. I believe what Young is suggesting here is 'analogies' implicit in everyday language, i.e. in 'lay-man's terms' to classify and organise the hierarchy of conditions. For these women then if UI was not a significant or a 'real' illness the position it took within this hierarchy was at the very base.

This brings us to the second type of knowledge described by Young as empirical knowledge.

Empirical knowledge: UI is a natural cause of childbirth and old age

For the women in this study, classification of illness was dependent on the views of significant others, society and the mass media. Many conceptualised urinary incontinence as normal and as many related it to childbirth and ageing, which are both normal human processes. Antonovsky refers to this as *comprehensibility*, where the individual makes sense of illness processes, i.e. that urinary incontinence will occur after childbirth and as I get older. This view was encouraged by the minimal media coverage about UI. As Aisha stated:

'Well it's pathetic because people tell you about cancer but they don't tell you about this do they ... I mean like in school or college you learn things, obviously that's how you get to know things no one tells you that you may sometime in life suffer from incontinence or what to do to prevent it happening ... (Aisha 28 years old).

Partly due to this lack of media coverage the perception that the participants had of urinary incontinence 'not being a real illness' was persuasive. From the narratives of the women, it was evident that those who re-ordered their lives to accommodate leaking urine found it extremely difficult to control their anger and frustration due to the lack of media coverage, and their knowledge regarding this subject area. In Doshani et al's (2007) study similar views were also reported, however anger or frustration were not seen in that sample. Many claimed that they often became angry with themselves for not knowing why such problems occur. It can therefore be assumed that these women had low SOC. However self-management and religious ethics allowed many of the women to sway towards a strong SOC, as religion is one such concept that determines SOC (Antonovsky, 1979). Accepting the condition and

self-treating, allowed many to overcome the impact of UI on their lives to the best of their ability, which in Young's terms can be related to the third type of knowledge, 'rationalised' knowledge.

Rationalised knowledge: self-management strategies help conceal the problem

As noted above, in seeking to create balance between family and illness some participants self-managed their condition. They believed that, due to the natural causes of urinary incontinence, and the values imposed on them through the family, on balance this was the best option. Relating this back to the SOC we can assume that the way these women viewed UI was as a predictable and meaningful entity. They had the ability to be motivated to cope with the condition. The ability to cope reasonably well can also be understood through the cognitive sense of UI, as ordered, consistent and structured. From this perspective, it becomes the norm, falling within Antonovsky's manageability concept. Women developed different coping strategies that allowed them to manage their condition without going against their religious, cultural and family norms.

'It is as normal as brushing my teeth [...] I do not let it bother me, I have just accepted it, it is a part of life I suppose' (Arifa, 37 years old).

The strategies that many had developed over the years maintained their sense of what I have termed 'the presentable self'. This brings us to what Strong (1979) describes as the self as an expert – *'since human action is embodied in the care and maintenance of our body ... we are obliged to be doctors to ourselves and to others ... as we acquire and refine a variety of medical theories, diagnostic procedures and treatment practices'*. By self-managing participants became 'lay experts', managing and balancing their own conditions and their health. Self-management refers to the activities people undertake to create order, discipline and control in their lives. Lorig and Holman (1993) state self-management gives the sufferer a 'sense of control over their lives'.

Young articulates that each person knows a variety of medical facts that they may draw upon to understand and manage their condition. Women's knowledge about UI was in fact gained through self-managing strategies, making them valid. Restricting fluid intake after a certain time in the day (Doshani et al 2007), wearing pads to prevent a leakage and restricting strenuous exercises are all strategies for dealing with UI.

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It is normal as pushing my taint (...) I do not let it bother me, I have just accepted

their religious, cultural and family norms.

copied strategies that allowed them to manage their condition without going against falling within Antonovsky's 'manageability' concept. Women developed different, ordered, consistent and structured. From this perspective, it becomes the norm, reasonably well can also be understood through the cognitive sense of UI, as They had the ability to be motivated to cope with the condition. The ability to cope that the way these women viewed UI was as a predictable and meaningful entity, on balance this was the best option. Relating this back to the SOC we can assume causes of urinary incontinence, and the values imposed on them through the family, participants self-managed their condition. They believed that, due to the natural As noted above, in seeking to create balance between family and illness some Rationalised knowledge, self-management strategies help conceal the problem

'rationalised' knowledge.

their ability, which in Young's terms can be related to the third type of knowledge, self-testing, allowed many to overcome the impact of UI on their lives to the best of

Self-managing of UI implies a high probability of changing life circumstances, for example, avoiding leakage by restricting fluid intake and daily wearing of pads. How these women adapt is related to their sense of coherence, and mainly to the concept of manageability. For Antonovsky the component of manageability defines the extent to which one perceives that resources are at one's disposal which adequately meets the demands of the condition (1987; pg 17). These women managed leaking urine, by working out ways to prevent a leakage, and ways of dealing with leakage.

Inter-subjective knowledge: talked over with others

Self-management and concealing of the condition was closely related to cultural upbringing. The term language refers to a system of symbols that are used to communicate information and knowledge (Young, 1981), although Young refers to this as a dialectical process, of obtaining knowledge, thinking, knowing, remembering, categorising and problem solving.

Many women in the study had preconceived ideas regarding leaking urine. Many stated that it was not a subject for discussion, relating it to the vaginal area. Others felt that, as it was a natural consequence of childbirth and old age, there was no point discussing it, as every woman will have this condition (Doshani et al 2007). Findings in this study have further developed on the study by Doshani as religious and cultural beliefs about UI are explored. In this study some women would resist using terms such as vaginal area or bladder to relate to urinary incontinence, as many had ascribed the meaning of 'the dirty area', to places where bodily fluid is dispelled. 'Dirty work' or 'bodywork' is a term used by Twigg (2000), which refers to areas of human waste (vaginal or rectal), which are seen as particularly problematic within any cultural group (Lawton, 1998). This process of ascribing meaning is described by Antonovsky as the development of orientation, which is based on 'learned behaviours' that are taught or observed through childhood, and that influence and shape the way the individual perceives the world and themselves. In this study it was the culturally taught and religious orientated behaviour that modified the way these women viewed the whole area of leaking urine.

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Culturally driven meanings of urinary incontinence were related to the female genital area by the participants, an area that was considered 'dirty' or 'naphak'²¹ (Twigg, 2000), and which was unacceptable to discuss. Leaking urine within the Islamic perspective then violates the 'pakh' 'naphak' concept, which is highly regarded within the Muslim communities, and relates to ablution or 'wadu' – cleansing of certain body parts with the intention to worship (Al-Misri and Keller, 1994). Therefore, when bodily fluid is released intentionally or unintentionally from the body the person becomes impure or 'hadath'²². Such bodily fluids include urine, excrement, blood, pus, and vomit which are known in Islam as filth or 'najasa'. These terms are detrimental within the Islamic perspective as they restrict Muslims from performing and worshipping Allah. Ablution is the only way this can be corrected. However, continually leaking urine caused barriers, as many participants disclosed.

The naphak nature of leaking urine was also related to impurity of the body which further imposed fear on many women, as found in previous research relating to 'leaking in inappropriate places' (Mitteness (1987). 'Fear others could smell the odour' and 'fear of underlying causes' (Lagro-Janssen et al 1992) were all concerns for the women in this study. Synnott (1993) states odours, which either are perfumed or 'foul' smelling in our society, become a symbol of the self and smells are converted from physical sensations to symbolic evaluations. Brittain and Shaw (2007) relate such a concept to urinary incontinence, *'odours carry with them a moral labelling and symptoms become a stigmatising condition'*, which for many sufferers becomes a 'fear' of being labelled abnormal. It is not surprising that many of those who suffer from such a condition either self-manage, do not seek help, or withdraw from society altogether.

As can be seen from the above, culturally driven behaviour regarding the overall concept of UI was embedded within each individual from early childhood. Meaningfulness, manageability and comprehensibility were strongly linked to cultural norms. In this case, maintaining a strong sense of coherence appeared to be linked to a capacity to keep the balance between UI management and religious hygiene. Women used language that normalised UI, unless they felt UI caused a barrier between continuing their religious duties, i.e. were out of balance.

²¹ Naphak: direct translation of this term refers to dirty, as is the view of many Muslims especially when related to dispelling of bodily fluids.

²² Hadath – meaning the things that nullify one's ablution (Al-Misri and Keller, 1994).

Culturally given meanings in an individual's world (Kleinman, 1987, p. 10).
even by the participants, and on the other hand, a sense of ownership of the
2000), and which was the subject of a study by Kleinman (1987, p. 10).
perspective that values the cultural context of the individual's experience
the Muslim communities and their relationship with the dominant culture.
paths with the intention to understand the cultural context of the individual's
field is released information, and the individual's experience of the field is
impute or 'read'. Such a study is a study of the individual's experience of the
world which is known to the individual, and the individual's experience of the
the Islamic perspective as they are known to the individual and the dominant
Alibi. Alibi is the only way to understand the individual's experience of the
une caused harm, as they are known to the individual.

The negative nature of looking at the world from the individual's perspective
further imposed fear on individuals, and the fear of being labeled as
feeling in inappropriate places. With the fear of being labeled as
other, and fear of underlying of being labeled as other, the individual's
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(2007) relate such a concept to the individual's experience of the world.
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¹⁰ Islamic orientation of the individual's experience of the world is a part of the individual's experience of the world.
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Negotiating knowledge: reinforced by significant others

The process of understanding UI as a private concept which should not be disclosed to others was increasingly reinforced by significant others, namely mothers and sometimes health care professionals. Those women who had begun the process of seeking help usually informed their GP or practice nurses, who informed them 'that it was a normal part of ageing', this was also found by Doshani et al (2007), for full quotes refer to chapter eight 'its the norm'. What Young suggests here is that their empirical knowledge (that UI may be a problem) was unreliable; while knowledge negotiated by the professionals becomes credible (she is a nurse/doctor they know what they are talking about).

For those women that sought help the negotiating knowledge was related to the severity of leakage that interfered with the daily activities, which influenced help-seeking behaviour. These women were referred to continence professionals who, many expressed, also reinforced the belief that UI was related to childbirth. However, a few of these women had either not given birth or had had caesarean section, making the negotiated knowledge of the health care professionals false and misleading.

Young states that in the five-fold model of medical knowledge, all five concepts are as important as each other, as they are connected to specific intentions and acts. The relationship between the five kinds of medical knowledge is dialectical (Young, 1981). Similarly Antonovsky's model of SOC is as valuable, as this allows the understanding of health, illness and disease through subjective experiences of the individual and not through the commonly held biomedical view.

Summary

The study undertaken by Doshani et al (2007) has provided a beneficial stepping stone for this study. However, it did not specifically take into account the cultural and religious impact of UI on a religiously motivated group. This study is the first to consider such an impact. In summary, in this study, most of the women appeared to have a strong sense of coherence, as expressed in their capacity to interpret their experience of UI as meaningful (God's will) manageable (through their various approaches to the balancing act) and comprehensible (through normalising lenses of old age and childbirth consequences). This was manifest through the self-managing strategies (rationalised knowledge) that many had adapted that allowed discovery of

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ways in which leakage could be prevented. Also the belief that UI was normal and would happen with advancing age increased the sense of coherence, as the condition did not come as a surprise (empirical knowledge). Within the Western view of medicine, assumptions of rational behaviour do not correspond with the subjective interpretations of behaviour that took place in this study. Within this view rational behaviour for these women would be to seek help, or if they refuse, as many did, it is assumed that irrational decisions are made. Applying Young's inter-subjective concept allowed exploration about urine incontinence, which was for these participants embedded knowledge within their cultural and religious framework (theoretical and empirical knowledge). The positions they adopted to bring balance (self-manage, illness role adoption, or, in extremis, help-seeking) were highly rational within that context.

When speaking of their experiences, participants appeared to make connections between their health and other life events, mainly family issues and most importantly their religion (inter-subjective knowledge). Their understanding of UI was filtered through their cultural, religious and family upbringing, or in Antonovsky's words, through the development of orientation, which is likely to be relatively fixed by the time individuals reach their mid-twenties. This was regularly reinforced through their religious teachings. These concepts are very unlikely to be altered, as they are deeply rooted within a group who already feel 'targeted' due to their religious beliefs. This caused retrenchment back to family and religious values, which in turn, increased resistance to the standard biomedical treatment model for UI.

Combining the models of Antonovsky and Young permits an understanding of how the participants constructed logical models of health and illness that reflected not only their own personal perspectives on managing and coping, but also the way society constructs such conditions, primarily within the Islamic perspective.

Young argues that 'cognitive structures', as proposed by Rational Man theory, do not include instances where 'an organising principle is embedded' in the behaviour, social relations, and material equipment that people use in order to produce their knowledge of sickness and to shape sickness in socially recognisable and acceptable ways. In contrast, Young claims that people use a particular sickness episode as a prototype (standard) for organising and understanding other sickness episodes (Young, 1981). Young's theory within this context is that having constructed UI based on the history and linguistic semantics of their culture, what these women

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do in terms of coping, managing, and continuing their religious obligations, makes sense. These women may not understand UI, according to the explanatory or biomedical model, but they understand it in an equally valid way – through their religion. For a non-believer then understanding these women through their religious and cultural knowledge is as difficult as the patients understanding the biomedical or Western view of illness, UI etc (Young 1981).

Solution

The findings of the current study offer a basis for constructing a contextually situated model for such a proactive approach. Based on these data, health care professionals in areas such as UI or general gynaecology need to understand these women's perspectives through a dual lens: both within the biomedical model, and importantly, through the subjective experiences of the condition that render it meaningful, manageable and comprehensible, or, in Young's words (1981, pg 326), through their personal theoretical, empirical, rational, inter-subjective, and negotiated representation of UI:

- Treat each women as individuals
- Assess the meaning and implications of UI to each individual
- Find out what religious restrictions apply to
- Find out what women have already done
- Find out what patient's are expecting
- What have these patient's tried already
- What do these patient's require
- What are the consequences of this

The following diagram illustrates a possible model for this purpose. Such a model could be helpful in determining what has been achieved by each woman, whether she is a member of a religiously orientated group or of the general population. The illustration below is drawn from Naila's narrative, to show how this model can be used to understand her concept of the problem and what steps she has taken.

Table 7 Possible model: Naila's narrative

	Meaningfulness	Comprehensibility	Manageability
Theoretical Knowledge	<i>Not a real illness</i>		
Empirical Knowledge		<i>Natural part of ageing and childbirth.</i>	
Rationalised Knowledge	<i>Can manage through pads. Severity of the condition.</i>	<i>God is in control of what happens in my life.</i>	<i>Pads, less water.</i>
Inter-subjective Knowledge		<i>Dirty, should not be talked about. Should not expose in front of men.</i>	
Negotiating Knowledge	<i>Not real illness, as not perceived through significant others and the media</i>	<i>Health care professionals state it's normal</i>	<i>Seek help, pads, and exercises.</i>

In the following chapter, I will revisit the aims of the study, and how these have been met. I will provide some conclusions and recommendations for future work.

Chapter 13

Answering the 'So what' question

The original aim of this study was *'to explore the religious and cultural influences on help seeking and decision making in South Asian Muslim women with UI and how these influences impact on their daily lives'*. In chapter four (pg 113-114) I discuss how and why the aim was changed to *'the meaning of urinary incontinence in the South Asian Muslim women'*, taking into consideration their religion their culture and their lived experiences.

Continence services in the Northwest of England are rarely utilised by the South Asian community. Primary evidence, although limited, suggests that 1 in 10 Muslim women access these services, compared 9 in 10 White women. These differences can be due to many factors, and can include their perceptions and understanding of UI, the perception of the services provided, social, cultural and religious factors. To understand these constructs phenomenology as a methodology was applied to this study as it seeks to understand another's experience (Cohen et al 2000). The meanings that the 41 South Asian Muslim women attribute to their experiences help create the needs they have and how these needs can best be met.

In this chapter I will consider to what extent the aims of the research have been met as well as attempt to answer the 'so what' question about this research. Moreover, I will discuss the implications of this research both on a theoretical and practical level before looking at some of the limitations of this study and suggesting how these could be addressed in future research. Finally, I will suggest some possible research avenues that could follow on from the findings generated in the context of the thesis.

Overview of the process

The initial question arose through the lack of published literature which was specific to Muslim women and urinary incontinence. This was confirmed by local statistics that many South Asian Muslim women in the study area do not utilise the continence services provided. To seek an understanding of this, the research question was developed.

I interviewed 41 South Asian Muslim women, 27 women in the community who had not sought help and 14 women who had sought help through continence clinics. The comparative nature of this study was to explore 'the meaning of seeking help'.

Interpretations of the data illustrated that these women performed a balancing act.

Answering the Call for Action

The original aim of this study was to explore the experiences of South Asian Muslim women seeking help seeking and decision making in relation to their reproductive health and family planning. These influences impact on their lives and the way they live. The aim was changed to explore the experiences of South Asian Muslim women taking into account the influence of their lived experiences.

Contraceptive services in the workplace, in the home, and in the community. Primary evidence from women's experiences of contraceptive services, compared with the experiences of women who do not use contraceptive services, can be due to many factors, and not only to the quality of the service.

At the beginning of the service provision, women who do not use contraceptive services are understood these contraceptive phenomena. The aim of the study was to understand the experiences of South Asian Muslim women who do not use contraceptive services. The aim of the study was to understand the experiences of South Asian Muslim women who do not use contraceptive services. The aim of the study was to understand the experiences of South Asian Muslim women who do not use contraceptive services.

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Major findings

This study has shown that urinary symptoms caused misery, embarrassment, regret, and restrictions for some participants, whilst others self-managed their incontinence symptoms successfully. The study suggests that it is important to look at all aspects of the individuals and factors that will influence them seeking health care, and not just the illness or condition the patient presents with. Applying the salutogenesis framework developed by Antonovsky allowed 'generalised resistance resources' to be taken into consideration. These include material resources, knowledge and intelligence, social supports, religion and an individual's state of health (Lee, 2005; pg 3). The five-fold medical knowledge model by Young (1981) draws attention to patients as logical beings constructing an understanding of how and why an illness may have occurred, that may not reflect the biomedical model. This is equally important in promoting understanding. Young stresses that allowing patients to express the logical rationale of their assumptions about the presenting condition can be gained through his five-fold model.

While the results presented echoed views and perceptions held by White women on urinary symptoms (Abrams et al 1990; Ashworth and Hagan 1993; Irving et al 1998; Chapple et al 2000; Chapple 2001; Avery et al 2004), there is evidence suggesting Muslim women can have additional anxieties and difficulties, especially in relation to their religious beliefs.

The sub-aims within the overall aim of this research were *'to explore beliefs about urinary incontinence amongst these women'*, and *'to understand help-seeking behaviour amongst women who had sought help and women who had not sought help'*.

South Asian Muslim women in this study who had and had not sought help assigned similar meaning to the concept of urinary incontinence. Urinary incontinence for these women was a normal part of ageing and a natural consequence of childbirth. These findings are also reported in previous research (Foldspang et al 1992; Grimby et al 1993; Ma 1997; Pinnock and Marshall 1997; Torres et al 2001; Abrams et al 2002; Contreras Ortiz, 2004).

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The term urinary incontinence did not hold any meaning for the participants. Their lack of knowledge restricted their understanding of why this topic was an area to be

researched. Urinary incontinence was a condition related to the female genital area, a dirty area, where bodily fluid is excreted from; an area that should not be discussed with anyone, not even family members.

Women in this study attached social stigma to urinary incontinence which is reported in previous research (Herzog et al 1988; Grimby et al 1993; Melville et al 2005). As identified within this study people who hold these beliefs tend to delay seeking treatment, relying on either self-management or denial, which, as a consequence may cause symptoms to worsen (Shaw, 1999).

On the surface it appeared that the reason why the participants in this study refused to seek health care for urinary incontinence was due to the belief that it was a normal part of ageing. Only when explored further did the daily external pressures that prevented them from seeking help become apparent. Many had developed self-management strategies that can sometimes be imposed by professionals as primary prevention. These methods included fluid restrictions after a certain time in the day and wearing pads. Restrictions were also imposed on the lives of participants in the study by external factors such as society's attitudes towards 'leaking urine' and their role as Muslim women. Within the Islamic regulations, leaking urine is a form of 'naphakness', which relates to the body being dirty.

"So what"?

Applying a model that concentrates on the individual's understanding offers a more complex, holistic understanding of salutogenesis. It takes account of faith and marginalisation, and allows us to move care towards the WHO/Islamic views of 'health' rather than the narrow linear 'normal medicine view'.

The 41 South Asian Muslim women who took part in this study indicated that the lack of media coverage regarding urinary incontinence reduced their knowledge about urinary incontinence, which inevitably restricted them seeking health care. Many were aware of the common health concerns, smoking, obesity, lung cancer and so forth, as these were regularly telecasted. The belief that urinary incontinence was not a condition where help should be sought was encouraged by the lack of coverage. It is also worth noting that many of these women were unable to read English or any written language, for example Urdu or Punjabi, therefore translated documents or

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health information for these women were not appropriate. Therefore, simply providing translated documents would not be viable nor would watching channels that communicated in English. The lack of coverage was also related to the Asian channels that many of these women subscribe to. Providing health information on these channels may be a way forward.

Many women talked about 'get together' or one to one sessions, just for women, where health issues that only relate to their needs could be discussed. Group discussions have been provided by the local Trust relating to urinary incontinence, headed by a physiotherapist, and accompanied by an interpreter. However, correct information is not always relayed.

The Muslim women in this study repeatedly requested that such information should only be provided by a woman who understands them, their religious and cultural practices, and their understanding of urinary incontinence. Understanding and appreciating these women's cultural and religious values, views and beliefs, can enhance interest in promoting caring in all aspects of health behaviours, health intentions, and health actions. Relating back to the salutogenesis concept and Young's critique of the Rational Man position, this understanding would take into account the individual's concerns. It would not be disease specific but would also incorporate women's knowledge and understanding of health, illness or disease.

It is a common belief that many Muslim women will refuse examination by male health care professionals. Through this study I have been able to distinguish that this was not a matter of Muslim women being 'awkward', rather it is a culturally driven behaviour and a misinterpretation of the religious tenets.

Religious beliefs state '*a Muslim woman requires the permission of her husband where intimate examination is necessary*', or that '*if a male doctor is only available then the woman should be accompanied by her husband*' (Al-Misri and Keller 1994, pg 514). Clearly, religion does not restrict women seeking health care, but due to culturally driven behaviour women are taught not to discuss female health concerns or the genital area with their husband. Thus if women culturally cannot discuss UI with their husbands, as it relates to the genital area, then they cannot seek help as religion requires them to inform their husband prior to seeking health care, where examination is a must.

health information for these women were not appropriate. Therefore, simply providing translated documents would not be viable nor would waiting channels that communicated in English. The lack of coverage was also related to the Asian channels that many of these women subscribe to. Providing health information on these channels may be a way forward.

Many women talked about 'get together' or one to one sessions, just for women, where health issues that only relate to their needs could be discussed. Group discussions have been provided by the local Trust relating to urinary incontinence, headed by a physiotherapist, and accompanied by an interpreter. However, correct information is not always relayed.

The Muslim women in this study repeatedly requested that such information should only be provided by a woman who understands them, their religious and cultural practices, and their understanding of urinary incontinence. Understanding and appreciating these women's cultural and religious values, views and beliefs, can enhance interest in promoting eating in all aspects of health behaviour, health intentions, and health actions. Referring back to the salutogenesis concept and Young's critique of the Rational Man position, this understanding would take into account the individual's concerns. It would not be disease specific but would also incorporate women's knowledge and understanding of health, illness or disease.

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The above religious statement is complicated further by the fact that *'Muslim men are forbidden to look at their wife's genitals and vice versa'*. Therefore, it is not surprising to see why these women refuse to seek health care from male professionals, who at the end of the day are strangers.

Women who had sought help for their UI generally felt let down by health care professionals. Many had specified the need for a female doctor, but in the end were treated by male consultants. In line with Doshani's (2007) findings, some felt ill-treated by professionals, due to lack of acknowledgments of their specific beliefs. Whilst some women noticed an improvement in their urinary symptoms, many felt sinful due to their religious beliefs. This is one of the major findings of this study, which links guilt and alleviation of symptoms together.

Within the models I proposed it is possible to take into account that physical health does not necessarily equal salutogenesis and to move beyond the linear definitions of health towards the WHO and Islamic definitions of health. These take into account women's own perceptions, not just ours as health professionals. Through Antonovsky and Young's model, we can move beyond repeating the findings in previous research. For example in chapter 12 I have provided a table format of a narrative which allows us as health care professionals to understand what the meaning of UI was for this woman (pg 228). This format allows identification of factors that need to be considered when commencing on a care pathway, for example self-management strategies and their need.

The model proposed can also be applied to patients in a range of situations by providing a clinical template that takes into account individual factors. Allowing professionals to capture the subjective 'meaning' of a condition and acknowledge that experienced illness, disease or condition do not usually lead to precise models. This model allows for 'emotions' and spirituality to become part of the overall process.

Taking into account concerns, opinions and views about treatment options are also important within this model. Through the findings, it can be observed that many of the participants had tried to help themselves. When this did not work, they were forced to break away from cultural restrictions placed on them to seek help. Many were not happy with the service they received, as most of these women believed they would receive a surgical option, which was not always the case. Primary management

The above religious statement is a common one in the South African context. It is often used to justify a lack of concern for the poor and the sick. It is a statement that is often used to justify a lack of concern for the poor and the sick. It is a statement that is often used to justify a lack of concern for the poor and the sick.

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when seeking continence services requires professionals to take a detailed history of each patient, however self-help questions are rarely asked. The patient presenting with UI symptoms will usually be advised to begin non-invasive treatment, i.e. daily intake, exercising etc. This may be something they have already tried.

I believe that applying questions relating to self-treatment or self-management to consultations would allow professionals to discover why patients are not satisfied with the services we provide or why non-compliance becomes an issue. Patients may not understand all the physiological aspects of leaking urine but do try to alleviate their symptoms, therefore becoming 'lay experts' (Young, 1981). Using the model may reveal this, and prevent health professionals advising more of the same for someone who has taken big spiritual risks to come for health care.

The literature has indicated that general practitioners and practice nurses are reluctant to approach the topic of urinary incontinence. What we need to understand is that these women will not disclose such conditions without encouragement. As identified through the narratives, many of the women became embarrassed as discussing such a topic is not considered culturally appropriate. It has also been reported that cultural myths regarding urinary incontinence, i.e. that it is a 'normal part of ageing', are also encouraged by professionals, as the topic becomes uncomfortable for both to discuss. If professionals are unlikely to instigate the conversation, nor are the patients in our care. This leads to needs not being met. People may not always address their health problems when meeting health care professionals. This is particularly true of UI, which can restrict social movement and increase isolation and loneliness.

Primary health care professionals play a vital role in screening for such conditions. This is another reason why there may be a low uptake of continence services, especially if these professionals do not detect such conditions. Brown et al (1997) states that if professionals do not specifically ask questions related to UI then patients are less likely to instigate this conversation. Therefore detection rates remain low, unless it is especially looked for (Brown et al 1997, Byles 2000).

Summary and Contributions to knowledge

The above sections have drawn together the findings of this study in relation to previous literature on urinary incontinence. Urinary incontinence is generally a well-

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The above sections have drawn together the findings of the study in relation to previous literature on urinary incontinence. Urinary incontinence is generally a well-

researched area. However gaps are evident specifically to urinary incontinence and the Muslim population.

This study appears to be the first to explore the meaning of urinary incontinence in the South Asian Muslim community in the Northwest region of England. Previous studies have provided a 'snap shot' of this phenomenon in general (Haggar 1994, 1995; Wilkinson and Williamson 1995; Chaliha and Stanton 1999; Wilkinson 2001); however, none have been as in-depth as this study.

The impact of leaking urine on the Muslim woman was acknowledged by Chaliha and Stanton (1999) who found urinary incontinence restricted religious activities as this related to the need for cleanliness at prayer. This concept was taken further in this study and explored. Participants were asked *'if leaking urine restricted their religious activities why is help not sought, and how this affected them'*.

To begin with, the term urinary incontinence did not have any meaning for South Asian Muslim women in the study. Their understanding of UI was similar to that reported in previous studies in this area (Abrams et al 1990; Ashworth and Hagan 1993; Irving et al 1998; Chapple et al 2000; Chapple 2001; Avery et al 2004; Doshani et al 2007). South Asian Muslim women in this study understood leaking urine in terms of their religious, cultural and family practices. From the religious perspective, urinary incontinence was a 'naphak' concept, one that restricts the continuation of performing prayers. It is one of the fundamental practices of Muslims to pray namaz five times day at different intervals. Participants initially denied that UI restricted their performance. Only through further exploration participants admitted that they had either leaked urine, or had not prayed for a number of years. The psychological and emotional impact that UI can have on Muslims especially in relation to their religious commitments was immense. Similarly due to their cultural taught behaviour and family practices, many denied the condition as discussion regarding the female genital area to others including family members was a forbidden act. For such reasons many of the South Asian Muslim women in this study had suffered in silence and self managed their conditions.

Secondly, non-compliance was evident in this study. Previous research has repeatedly reported high non-compliance rates in the South Asian communities (Mackeigue et al 1992, 1993, Wallace et al 1996, Rankin & Bhopal 2001), without exploring further why this may be the case. This study explored this concept to gain insight into why people do not comply with treatment regimes and management plans in relation to urinary incontinence. It was understandable that seeking healthcare for

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South Asian Muslim women for symptoms of UI was not a necessity due to religious and cultural restrictions, therefore many self managed and coped reasonably well. Only when the severity of leaking urine increased, or a leakage happened in the presence of family member's participants sought help. It is important to acknowledge that many of these participants suffered from UI for a number of years, they had managed their conditions and had become lay experts in controlling and preventing leakages.

When these women sought help from continence services provided, they all began treatment with behavioural techniques such as fluid restriction, fluid diaries, pelvic floor exercises, or oral medication. Non-compliance to these techniques was high in this study, although it appears that this may be related to a lack of communication between the provider and the patient, it is much more profound. It is important to understand that many of the women who sought help did so by breaking away from long held cultural, religious, and family held views, on urinary incontinence and intimate examinations by male healthcare professionals. These women had suffered for a long time and were hoping for 'a quick fix', which would allow them to continue with their religious obligations and seek forgiveness from their God due to breaking away from their belief system by taking big spiritual risks to come for health care.

This contribution to knowledge identifies that although non-compliance rates may be high, the reasons are viable in relation to the participant's religious views, which was a fundamental part of their being.

Self-management strategies carried out by individuals are rarely discussed in consultations, and are usually the cause of non-compliance. Patients may not understand the physiological aspects of UI, but their understanding from a personal, religious or cultural perspective is as important as the biomedical view.

Further, I believe acknowledging the importance Muslims place on their religion is vital, every aspect of their lives is centred on Islam. Health and wellness are the greatest blessing to Muslims from their God, illness and misfortune are also considered as blessings as they are a test from their God, or punishment of sins. Therefore, many accepted 'ill health', in the hope to be pardoned for causing sin. For such reasons many Muslims will delay seeking help (Rassool, 2000). Religion was also a source that instigated help seeking behaviour in participants who had not sought help. These participants felt they coped reasonably well through self-management strategies, however when the concept of religious obligations was

considered with leaking urine did they realise that they were causing sin, by leaking and not completely focusing on prayers.

The possible model illustrated on page 237 is therefore an important and unique contribution to knowledge. It could be beneficial in providing care for religiously and non-religiously motivated groups, when seeking health care for urinary incontinence. This model takes into consideration individual understanding of UI, and more important the self-management strategies that people consider prior to seeking help.

Comparative aspects

In chapter four, I describe the comparative elements of this study. The first related to comparing two groups of South Asian Muslim women with urinary incontinence. Women who had sought help were compared to women who had not sought help. The reason for taking this comparative approach related to the lack of continence services accessed by Muslim women in the Northwest of England. The demographic data of this area was compared to the number of patients who accessed uro-gyneacological and gynaecological services (refer to pg 6-7). The figures provided a guide and an estimation of the type of services where accessed. This data suggests that 1 in 10 'Asian/Muslim' accessed services compared to 9 in 10 White women. To explain why there may be such a vast difference, I decided to recruit women who sought help and who had not sought help.

The reasons are clear as can be seen in chapter 8, 9 and 10. Both groups understanding of urinary incontinence was similar; it was a normal part of ageing and childbirth', and it was not life threatening as participants had other serious health concerns. Participants that had sought help did so due to increased symptom severity, and restrictions on religious obligations. For those who had not sought help, symptoms were not bothersome or severe enough to seek help, and many self-managed their conditions well.

The second comparative element of the study related to the age of participants. I decided to recruit participants from the age range of 18 years and over to allow exploration of practices and beliefs of younger and older Muslim women. Cultural practices are likely to change over time, for what one generation considers 'culturally acceptable' may not be similar to the next generation (Marwa 2000). The advantage of incorporating this range of experiences, practices and beliefs is the richness and depth of data obtained and the use of multiple perspectives to illuminate the

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phenomena under study. However referring back to the findings chapters, 6, 7, 8, 9, 10, and 11 there does not appear to be any difference in the cultural practices related to age. Cultural practices were so interlinked to their religious beliefs that participants did not appear to draw differences between the two. Cultural practices such as, employment, education, their role as Muslim women, help seeking behaviour, and examination by male health care professionals remained similar across generations. I consider this to be related to the wider understanding that participants felt rejected by the wider British society due to their religious beliefs, and continuing with religious or cultural practices allowed them to preserve their identity, practices, beliefs and values.

The final comparative element of this study relates to participants born in the South Asian countries against those born in the UK. This comparative element did not illustrate any differences in the understanding of UI (chapter 8, 9, 10), or their cultural (chapter 6) and religious practices (chapter 7). This also appears to be related to the fact that many felt alienated in UK, due to their religious beliefs.

There are a number of advantages to be derived from taking a comparative approach including the fact that differences found may serve to illuminate cultural identities of both groups. Although applying the comparative elements proved beneficial in understanding how views can change over time, they did not demonstrate any differences in cultural identity between those who did/do not access health care, age range or country of origin. For the participants in this study culture had become a fixed concept, a concept that is unlikely to change as it was so deeply embedded within their religious belief system.

Recommendation for research

In response to the 'so what' question, my reply would be that these findings show the influence that religion and culture can have on South Asian Muslim women with urinary incontinence. In an ideal world I believe more time and investment should be invested in providing health promotion, not just on urinary incontinence but also informing these women and their communities about what is written in their religious texts, in terms of examination by male health care professionals and seeking health care. Many women may take this as an insult to their beliefs and practices, although I believe that if a Muslim woman would organise and lead such health promotion sessions, we as professionals may be able to encourage the take-up of such

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services. More and more religious sessions regarding the teachings of Islam are held across the Northwest of England specifically for women, however unfortunately these are headed by Muslim men, which is not appropriate for these women as they are unlikely to ask questions regarding women's health.

The findings also suggest that this may be a difficult task especially where the area of religion is concerned. However I strongly believe, through my personal experiences and experience in researching this group of women that people are willing to discuss religious texts or beliefs that have been labelled as religious. This is another key finding of my research. Some authors have tried to explain how some minority groups link the significance of events to supernatural logic, or how staying healthy is seen as a matter of chance, fate or God's will (Donovan, 1986). While these studies have played a valuable role in understanding, it is of limited use in helping to understand the impact of urinary incontinence and the disabling nature of it on sufferers' lives. This study has provided valuable insights into how religion can impact on health. It appears that this may be the first study to explore the concept of UI in a religiously motivated group. Similar studies may also provide new insights into how other religious groups may be affected by UI, religion and health.

Recommendations for practice

We cannot change people's practices or beliefs, but we can inform them or discuss their concerns by referring back to their religious views. Five recommendations are suggested:

1. Use the new model in practice. As this would allow professionals to consider concerns, practices, and values of the patient.
2. Be aware of the need to ask about UI routinely. Urinary incontinence is not a topic that the patient will openly discuss, especially if it is not instigated by the health care professional. Simple questions about bowel and bladder functions are a necessity.
3. Provide health promotion. Understanding the needs of the population prior to providing written documentations, or group sessions.
4. Discuss the genesis of cultural practices. Talking to patients about their lifestyle and understanding that everyone is different and unique in their own right, not imposing our beliefs onto them.

5. To understand patients' view on 'health' or 'illness' whether that is from their religious or personal perspective may be a way forward.

The 'possible model' illustrated on page 236-237 offers a proactive approach to providing health care. This model could allow health care professionals in area such as uro-gynaecology to understand the needs of their patients. The model is 'dialogical' between the patient and the provider, offering the dual lens of biomedicine and subjective experience. This model is not specific to 'urinary incontinence' but could be applied to other conditions, where the aim would be to gain a deeper understanding of why and how an illness or condition occurred, how patients feel about a given phenomena, and what meaning they apply to it. The fundamental aspect of this model refers to self-management strategies that are more than often not considered within consultations. This lack of recognition of personal illness expertise leads to non-compliance with treatment management, as was evident in this sample. According to (Shaw 2001) prior to seeking health care, patients are more likely to consider treating themselves. When these strategies have failed and symptoms become bothersome people seek professional help. Therefore it is highly important to take these strategies into account, which can only increase the likelihood of compliance and success rates, whether the patient is a member of a religiously orientated group or of the general population.

A move from recommendations to action

A simple strategy for informing and disseminating findings is through verbalising the findings for patients and professionals, noting that the target language will be different. Planning and organising a workshop or training events for professionals through the narratives of the women in this study may help to appreciate their perceptions and beliefs. By this I am suggesting and have provided a session where I disseminated the findings from this study to the MDT urology team at the study site. These professionals were in direct contact with the participants in this study as those who had sought help were under their care (participants remained anonymous).

I have also presented the narratives of the participants at an ACA conference (Association for Continence Advice) there response was that of great interest in my findings.

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6. To understand patients' view on 'health' or 'illness' whether that is from their

I have provided sessions to Muslim women in the community to provide awareness of continence services. This was aided through an antenatal sessions held by a hospital translator.

Finally I will be submitting papers from my thesis to nursing journals.

Limitations of the study

A phenomenological approach attempts to explore meaning and is useful when the prompting question is to understand an experience as it is understood by those experiencing it (Cohen et al 2000, pg 3). Therefore, this study aimed to explore cultural and religious influences on help-seeking behaviour in South Asian Muslim women with urinary incontinence.

A major limitation of a hermeneutic phenomenological study is that the findings only present one interpretation of the data and therefore cannot be generalised. The sample size in a hermeneutic study is typically small and is a way to observe the richness and complexity of the experience and to provide in-depth knowledge on the given phenomenon. Forty-one women participated in this study, although this may be considered a small sample by some, the in-depth knowledge and experiences uncovered was vast. It was anticipated at the start of this study that the more participants that were involved the richer the data would be, however as the data in this type of study is vast, recruitment continued until data saturation was reached.

Due to demographic data of the study area, most participants were Indian, Pakistan or British. However, I did recruit two Muslim women who had originated from Kenya. I was not able to include women from other religious groups, therefore this study contains one specific religious group, cultural practices pertaining to that group, and one view of 'being'. Including other religiously orientated groups in future studies would be important as their views and practices can be explored to deeper our understanding of the impact of UI in these groups.

There are many types of urinary incontinence, however this study is generally covering urinary symptoms and not specific type of UI, therefore findings cannot be related to specific types of incontinence.

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Despite these limitations, it cannot be denied that the depth of information given by participants in this study provides valuable insights into their lived experiences of UI, their religion and their roles as Muslim women.

Conclusion

This study explored the religious and cultural aspects of urinary incontinence and the influence these factors have on the life of South Asian Muslim women. Through their words, the participants provided a sense not only of events and experiences, but also of the values, beliefs and cultural norms that influenced their lives. Overall, this study has shown that the 41 participants differed in terms of their responses to coping with symptoms of UI. These differences can be explored by the sense of coherence model and the five-fold medical knowledge theory. Sense of coherence explains individual-based coping resources (Antonovsky 1987), whereas Young's five-fold medical knowledge seeks understanding through the subjective experiences of individuals (Young, 1981).

Many different models on health, illness and coping exist in the literature and have been used extensively to predict and understand the overall coping mechanisms that individuals adapt when faced with life events. However, I believe that applying clinical or behavioural models cannot predetermine behaviour or illness, as everyone will not react and behave in the same logical manner as these models propose. I have used Antonovsky's and Young's model that does not concentrate on illness but rather on 'well-being' and is geared towards the subjective interpretations of the state of affairs and knowledge. This approach also postulates a dichotomous, qualitative distinction between a state of disease and a state of non-disease (Antonovsky, 1979; pg 66).

Government documents and policies relating to health are concerned with 'healthy living', maintenance, and delivering a high standard of care. Illness and disease, health and well-being as concepts are not well understood. It is also unclear how individuals suffer from illness and disease but remain 'well'.

Self-management, for example can be beneficial for quality of life. However, it can also cause symptoms to progressively worsen. It may also be relevant that many of the participants were older and had other conditions; therefore, suffering from leaking urine may have been the least of their problems.

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The final chapter in this thesis presents my own understanding of the sample, my prejudices, and how new horizons were developed. This presents the reflexive part of this study, as this is a fundamental part of the hermeneutic phenomenology, to provide one's own beliefs and self-reflection, which then becomes part of the overall research.

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Chapter 14

Reflexivity: A personal account

Introduction

In the previous chapter I have provided the overall discussion for this study, in which I have been able to answer questions that relate to any research project 'why is this important' and 'what new knowledge can I bring to this area'.

In this chapter, I will present my own experiences of the overall research project, how I matured as a researcher, a nurse and a Muslim woman. Many issues were raised through this process, which questioned my approach, my appearance, my preconceptions, my understanding and so forth. The process of reflexivity has allowed me to be aware of such experiences whilst experiencing them, taking them into consideration and view this diverse group as individuals. Such issues were related to the environment, family religion and culture, which allowed movement between 'parts' (influential factors) to the 'whole' (the individuals), in a pendulum movement. This pendulum movement was also maintained between the literature and my findings and further my interpretation of the findings.

Within the hermeneutic approach, reflexivity is necessary in shaping the process of interpretation and making explicit my own prejudices and preconceptions, which affect the data generated. The ability to identify my own prejudices throughout the research process proved to be beneficial as it allowed me to keep a diary of difficulties and achievements, which then helped with the 'writing process' that guided and shaped the study. Further, within the phenomenological approach, researchers are advised to identify their own beliefs about the phenomenon under study, and how their own personal beliefs may influence the findings (van Manen, 1990; pg 77).

'A lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of lived experience is there-for-me because I have reflexive awareness of it, because I possess it immediately as belonging to me in some sense. Only in thought does it become objective' (Dilthey, 1985; pg 223).

Within the interpretative approach I have taken in this study, my role as a researcher encouraged me to take an interactive approach between the participants, their environment and myself. This process was evident also through the data generated

and the overall research process, whereby the questions asked to answer the aims were reviewed regularly, in a circular manner.

The chapter will be presented in the manner through which the research process proceeded, starting with the opening title, literature review, preconceptions, contacts, translations, participants, interviews, interpretations, and the product. In all occasions I consider how I have developed, and how I questioned my own practices to form the interpretations.

The overall process

My interest in this area grew from my initial degree in nursing. Through the programme of study, I had the chance to complete a double dissertation. The title of the project was 'Diabetes within the Muslim community'. My interest in this topic area grew from my own experiences as a Muslim woman.

Following on from this I worked as a nurse in emergency care services in the area of study, where I was exposed to many Muslim patients. Again, I was unable to understand why many Muslim patients, especially the Muslim women, refused examination by male doctors, even if the examination was of the abdomen, and not genital area. I had linked such practices to 'embarrassment', rather than anything else. Examination where the woman has to disrobe in any society can be embarrassing, especially if the area exposed is the genital area, for example for pap smears, or vaginal swabs.

Developing an awareness of such practices, beliefs and views of the many Muslim communities was an area which I felt for me personally and probably for others would allow 'us' as health care professionals to understand why people behave, act and react the way they do.

Through the University of Central Lancashire, I was given the opportunity to apply for an MPhil/PhD studentship titled 'Racial aspects of urinary incontinence'. Urinary incontinence was one area I did not have much knowledge on, so to improve my chances at the interview, I completed a 10,000-word literature review. To my surprise, there was limited data on Muslim women and urinary incontinence.

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Initial preconceptions: 'naiveness'

In my first meeting with the supervisory team, I was given the task of drawing up ideas of what I would like to investigate. As I had already identified a lack of research conducted within Muslim women I decided to concentrate on this area, as it would also allow me to explore my historical encounters with this group.

The initial study title was: *'to explore the religious and cultural influences on help seeking and decision making in South Asian Muslim women with UI and how these influences impact on their daily lives'*. I felt very confident in researching this area, which I thought I was very familiar with, as Islam was also my religion, and I have been brought up in the Asian culture and community.

Establishing contacts

I began drawing up the demographic data of the population in the study area, as this was the area in which the fund holder wished to conduct the study. Drawing together the demographics of this area allowed me to identify the areas that the majority of the Asian population resided in.

I decided to attend events in this area that were targeted towards Muslim women. The first event I attended was an event ceremony for Muslim women. This was where I had my first encounter with their view of urinary incontinence:

'Urinary incontinence!!... no no if we had that problem we would be in hospital no one here has that problem, we do not have problems like that' (Event organiser).

The organiser of the event was clearly distressed that I had approached her during the event, which also made it worse regarding the topic area. I decided to change my approach and arrange one-to-one meetings with organisers instead of providing a group talk.

I decided to contact people who held health event days, namely community organisers within the areas identified. I became very cautious about the subject area, and did not want to offend people. Many of the organisers of such events were Muslim men, whom I felt at that time did not take me seriously. Maybe this was a gender issue. Many advised me to contact GP surgeries. Others were not interested in the study but had other desires. For me, this became the turning point: I became aware that people did not want to talk about urinary incontinence, which I had identified in the literature previously. My status as a Muslim woman did not really help me in this situation either.

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Through an informal conversation with a friend, I was advised to contact ESOL class organisers. The reason for this was related to government requirements. ESOL is a term used for 'English speakers of other languages', which has become a requirement for those intending to reside and gain residency within the UK. Luckily, for me these organisers were women, formal meetings held proved beneficial, and I was granted the opportunity to disclose the intent of the study to students in these classes.

Learning another language

Prior to verbalising the intent of the study, I decided to improve my verbal command of Urdu. As I was born in the UK, I have never had the need to communicate in another language, although now I can say that was also very naïve of me.

There is not one common language that all Muslims across the world speak. The Quran is written in Arabic, but only a minority speak in that language. Other religious texts like the Hadith are written in Urdu.

Taking this into account I decided to learn 'the more common' language of Urdu. This learning process was difficult for me. Understanding was not an issue, but using appropriate words was. Here I quickly learnt that there is no direct translation for the term 'urinary incontinence', and many other terms.

I was lucky in that my immediate family with whom I reside are all speakers of the Urdu language, and I suppose this helped me through this process, by them only verbalising in Urdu in my presence.

Translation of documentations

Through the decision to use Urdu as the main communication language I decided to translate all written material into this language too. Through my first student conference at the University of Central Lancashire I was approached by one of the lecturers who advised me to contact 'Lifeline', a well established translation company.

My inability to read Urdu was another issue; however, my mother helped me with this process, and read all the documentation to identify the appropriateness and readability.

Information packs

The information packs distributed to all potential participants included a covering letter, an invitation, information on the study, consent forms, demographic data, and an advertisement. All the information was provided in Urdu and in English (refer to appendix 8).

Verbalising in ESOL classes

ESOL classes are not only attended by women but also by men. In the previous encounter I had experienced I became aware that people are not willing to disclose their symptoms in a group or in front of the opposite sex.

I decided only to present, in Urdu, a very short introduction to the study relating it 'to women's health problems'. I decided not to use the term urinary incontinence or equivalent. The visual poster and flyers that I had distributed in the community centres also only provided information about women's health (appendix seven).

I attended ESOL classes from the period of December 2005 until July 2006; the verbal presentation of the study only lasted five minutes, as the time was allocated to the teaching of English language.

I practised my speech at home, in the presence of my mother and sisters, who most of the time would laugh – due to my struggle with the Urdu language, which I suppose encouraged me even more. The individuals in the ESOL classes encouraged me to speak Urdu.

The participants

Once the verbal disclosure of the study was conveyed, participants were asked to contact me on the number provided in the information packs, to answer queries that they may have with the overall process, their role and my role.

I decided to meet each potential participant and to my surprise found that many were unable to read the Urdu format of the documentation. Reasons related to the inability to read Urdu or any language. For this reason, I met potential participants in their own homes to talk through the study. There were also factors that participants felt inhibited the decision to take part in the study:

- Many participants felt that symptoms of the LUT was a personal matter, and felt information may be disclosed, many refused.

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- Some participants agreed to take part, however refused when informed the interview would be audio taped.
- Some participants felt they would need the permission of their partners, which meant that they would have to inform them that they had symptoms of UI.
- Religious obligations such as Ramadan and Eid were coming up during the time of interviews and recruitment.
- Family members such as daughters and daughters-in-law refused permission for their elders to take part, although the participants themselves agreed.
- Denial of the symptoms was one of the major barriers, as identified above.

Gaining participation in the interviews was an ongoing process, as participants identified others. Overall, 62 participants were contacted, and 41 participated in the interviews. Reasons for non-participation are identified above.

Interviews: the environment and the interpreter

Only when participants were fully aware of their role, my role and the intent of the study were consent forms signed, and a date arranged for the interview.

The interviews took place from January 2007 until January 2008. I conducted the interviews, on occasions with the help of a private interpreter, who was fluent in Urdu.

Many Muslim women refused to have the interpreter present, as they felt this was invading their privacy even more. They would allow a female family member to be present rather than an interpreter. Family members that were present through the interviews proved difficult, as they would speak for the participants, and interrupt the flow. On other occasions, participants disclosed information that caused embarrassment for the family members, regarding their personal and private life. Participants often indicated they had 'nothing to hide', although the facial expression on accompanying relatives indicated otherwise.

One elderly participant indicated the lack of sexual relationship she had with her husband due to leaking urine. Whilst the participant was disclosing this information, the relative left the room, indicating that she was going to bring refreshments. This identifies the belief that sexual matters are not discussed within the family circle, and should be kept private between the two people involved.

There were three ways then in which communication in the interview settings was conducted; firstly, there were those participants who requested to be accompanied by family members, for the purpose of communication. Secondly, others requested

Some participants agreed to take part in an interview without any compensation. Some participants indicated that they would only take part in an interview if they were compensated. Religious colleagues such as Priests, Rabbis, and Imams were approached for interviews and assistance. Family members such as daughters, sons, and granddaughters were approached for their ability to help with the interview. Denial of the syndrome was one of the most common reasons for not participating in the interview. Other reasons for not participating in the interview were the environment and the interview. Only when participants were fully aware of the study and its purpose, and when consent forms signed, and a date and time for the interview were agreed upon, did the interviews take place from January 2001 to January 2002. The interviews took place with the help of a research assistant who was trained in interviewing. Many Muslim women refused to have the interview in their homes, preferring to have it in a public place. They were interviewed in a public place, such as a mosque, a community center, or a public library. Family members were often present rather than an interviewer. Family members were often present rather than an interviewer. Interviews proved difficult as they would often be interrupted by family members. On other occasions, participants were not available for the interview. On other occasions, participants were not available for the interview. Participants often indicated they had no time for the interview. Participants often indicated they had no time for the interview. On accompanying relatives indicated of interview. One elderly participant indicated the interview was not possible due to her husband due to feeling tired. When the participant was not available for the interview, the relative left the room, indicating that the interview was not possible. The relative identified the belief that sexual matters are not discussed in front of the public. It should be kept private between the two people involved. There were three ways that in which participants took part in the interview. First, there were three participants who took part in the interview by family members, for the purpose of confidentiality. Second, there were three participants who took part in the interview by family members, for the purpose of confidentiality. Third, there were three participants who took part in the interview by family members, for the purpose of confidentiality.

the presence of the interpreter, and thirdly there were those who had no problems communicating in the English language.

Familiarisation with the cultural traits

As I have been brought up in a similar culture I was aware of the values my parents had imposed on me as a child, and practices that to date I carry out at home. For example, removing one's shoes on entering the house; taking refreshment offerings; and covering my hair with a scarf, especially in families that were religiously based.

In the initial meetings, I was able to identify for myself whether wearing my uniform or wearing formal clothing would be appropriate, however I learnt that these women were more likely to discuss and disclose information when I dressed in my uniform (nurse).

Islam and the Media attention: Radical Islam?

Prior to conducting this research study I did not necessarily interest myself with the terrorist's activities that had happened across the world. My view on life was that I was a 'British Asian'; religion for me was a very private matter. I would when possible continue with my religious practices such as fasting during Ramadan, praying namaz, and reading the Quran. Only through conducting this study did I realise the impact that religion can have on a believer's life.

Religion has become an important marker of self-identity for British Muslims. Religious identity represents the prism through which they see and interpret the world. The fundamentalist wave in Muslim societies has become a statement about 'protecting identity'²³. Media attention on Muslims began with the publication of the 'Satanic Verses' by Salman Rushdie in 1988, which fuelled anger in a range of groups. The Rushdie affair and the later Gulf War highlighted a number of British Muslims who became determined to defend their culture and religious identity, in a society where Christianity is the official state religion (IBA 2002).

²³ My own opinion – terror attacks have caused a considerable number of deaths, but Islam does not encourage such activities. Fear of Muslims is embedded in stereotypical assumptions and pronouncements regarding selected customs and, above all, the inherently fanatical, violent and irrational tendencies of some Muslim leaders and their followers. Much of the media attention is focused on the anger and violence within the Muslim communities, and less on the protection of Islam and cultural beliefs of the Muslim.

Non-believers may view such rituals as exotic or even extreme, in which the media has played a vital role. Prejudices and racial hatred towards a religious group are not uncommon in any country. People that appear and act differently than those who follow the predominant religion and culture, sense a fear of invasion, or a sense of fear is common, but understanding and acknowledging that not everyone or every believer is the same, is a start.

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Following the 9/11 (9/11/01) attacks in America and the 7/7 (7/7/05) London bombings, Muslims across the world were once again attacked for such horrific acts. These events have caused a minority of Muslim people to turn to extremism²⁴. Despite this, a recent poll in 2006 by the Washington-based Pew Global Attitudes (WPGA) project, found that 63% of Britons had a favourable opinion about Muslims. A slight decline from 67% in 2004, suggesting the London bombings did not provoke a rise in prejudice or racial hatred (Borger, 2006, 2007).

Only through reading about Islam, the history, the religion and the laws did I begin to understand that Islam as a religion has always remained in the attention of the media, whether positive or negative. In the book titled 'When the moon split' a biography of the prophet Muhammad (saw), Mubarakpuri and Richardson (2002) talk the reader through the violence and torment the prophet and Muslims faced, however the prophet reminded the followers that retaliating was not permissible. Islam, is a religion of mercy, and does not permit terrorism. The Quran states:

'God does not forbid you from showing kindness and dealing justly with those who have not fought you about religion and have driven you out of your homes. God loves a just dealer' (Al-Mumtahina, 60: 8 Quran).

Learning about the history, the Shariah law and the daily lives of Muslims was fundamental part to my study, a part that has allowed me to become practising Muslim, with the ability to understand why and how things originated.

My role as a researcher

Even though Muslim women were informed that my role at that point was as a researcher and not as a nurse, many discarded this information and requested information regarding their health, medication information, other hospital services, and requested me to accompany them to medical consultations.

²⁴ Extremism is forbidden in Islam. Hurting anything or anyone living or dead is a forbidden act. Terrorism has no place in Islamic thought, teaching or traditions. It is the opposite of everything that Islam stands for: Peace, Tolerance and obedience of God. Terrorism is a misunderstanding of this religion, and those who carry out such acts are misguided people. It should be noted that not only does Islam have misguided people but so do other religions. The fundamental beliefs and practices of each religion should be considered and not the actions of a few individuals. The media have a very strong influence on people regarding issues of religion and terrorism. After the 9/11 and London bombing, people who committed such acts identified themselves as Muslims, therefore Islam was viewed as a violent religion. The Arabic war 'jihad' has also been taken out of context and used to mean 'the holy war'; this is not a true translation of the word. 'Jihad' simply means 'to struggle' (Hadith, Quran).

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This placed me in a difficult situation, as I wanted to help these women, but at the same time was bound by my contract as a researcher. Once the interview was completed many of these Muslim women, especially the older women, contacted me to use my role as a 'nurse' to gain information. A few times, I had to refuse and inform them of where they could get such information. My refusal for these women was viewed as not helping them and as a Muslim woman it was my duty to help other Muslims. I felt guilty. However, I discussed such concerns with my parents, which helped me through this process.

My role as a Muslim woman

Throughout the interview process I was reminded on numerous occasions that as a Muslim woman I should stay home, not work and definitely not be divorced as I had brought 'shame' onto my family. My personal experiences, torments that I remember as a child and through my divorce, were once again echoed. My parents have five girls, which in an Asian family is seen as not a good omen. Muslim women would remind me of the fact that this was a bad thing for my parents, as Muslim women should have sons not girls. As a child I remember my mother quite distinctively asking my father to remarry, to which my father had responded by stating 'my girls are my boys'. This is the view of my father, someone who has guided me in my life and someone whose views matter to me. For this reason, I took on board what my participants told me. Comments that were targeted to me were ignored to a certain extent, but proved valuable for the interpretation process.

Interpretations, looking into religious texts and cultural myths held

The two important concepts evident in this study, I believe, are related to cultural and religious beliefs that Muslim communities hold. I also believe that religion is a concept 'that cannot be argued', for example if a believer of whichever religion states 'this is what is stated in my religion', how would an 'outsider' (non believer) argue against it?

Therefore, investigating the phenomenon of religion as a 'referential frame' required me to become aware of Islam as a religion or, as many identified, 'as a way of life' which subsequently prompted further areas to be explored. This led me to understand Islam as it is, not through the teaching of others, which I believe causes

many controversies, but gaining knowledge through the religious books provided (in English).

There is clearly a difference between religious teachings and mainstream schooling. In a school environment, we are encouraged to question, whereas, through my religious teachings, we were encouraged not too. Reading around Islam for myself has helped me a great deal. My preconception about my own religion has changed, and I believe this is for the better. Therefore, I felt I had the ability to understand what some of the participants born in the UK experienced.

Prior to commencing this study I was clearly narrow minded about my religious obligations, whereas now I can clearly and evidently state that religion does not restrict a woman living her life, she has the same rights as a Muslim man (Al-Baqara, 2:228, Quran). Such negative views are culturally driven thoughts, which many South Asian Muslim women encourage (Al-Musnad 1996, pg 313; Beishan et al 1998) refer to page 72-76. Unfortunately many South Asian communities continue common practices of segregation of genders, gender inequalities, and view women as second class citizens. These practices I believe have continued for generations especially within the sample as many felt 'alienated' in a British Western society due to their religious beliefs. Arrival of Muslims in the UK began, when men arrived for employment followed by their families (Shadid et al 1992). Through such population movements the UK embraced a host of different religions and cultures, and is known today as a multi-cultural society. Migrants have continued their cultural and religious practices, as a way of maintaining their identity/roots in a Western Christian society.

For example, Muslim women are less likely than the White woman to seek full time employment (Afshar and Maynard, 1994; Dale, 2001); this is due to cultural held beliefs that men are the providers and women the home makers. The Quran does not restrict women in seeking employment, as long as the sanctity of the family remains intact and a women's honour is not compromised (Al-Musnad 1996, pg 313).

Many Muslim women are unaware of their Islamic right which was evident in this study. All participants received their religious teachings from their parents and 'molvi Saabs' in the mosques. Unfortunately many of these women could not read the Quran or the Hadith therefore relied on their parents and elders of the family, who themselves were unlikely to have the ability to read these text. This circle has continued for generations, even though many younger Muslims are themselves referring to the original text, elders are very unlikely to change their views.

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Through the process of interviewing many older Muslim women, I became aware, no matter how many times I referred them to the original text of the Quran they were set in their ways. Religion and culture for the participants was one concept, as many felt '*without religion there would be no culture, and without culture no religion*'. Separating religious and cultural practices, values or beliefs was not possible, as this meant not following the religion correctly.

The remains continuous talk and debate around educating health care professionals about other religion, although this is important when providing care. I believe scholars and advocates should return to a fresh and immediate interpretation of the Quran (Stowasser, 1994, pg 38) and other religious texts, as many it appears through this study that many Muslims are unaware or have misinterpreted the texts. As Mernissi (1996) urges, it is crucial for Muslims '*to reinvestigate the normative religious texts*' to return to the texts themselves for interpretations and the true meaning of *being* and living a Muslim life.

In search of meaning

Interpretations, translations and transcription issues

In order to facilitate data analysis I translated and transcribed the interviews into English. Given that each data set was used as a basis for analysis it is a complex construction of a transcript of information input on behalf of the Muslim women, which was communicated through the help of a private interpreter and rechecked to ensure the data was not lost through translation.

Consequently, as I began the process of interpretation I immersed myself in the data and became part of it, seeking to understand what it must feel like to have such symptoms of urinary incontinence, an area that is not discussed at all. The facts uncovered were not separate from their meaning; neither was my perception, in the end, separate from the meaning of the women's stories in the text. What is presented in this thesis is my interpretation or meaning, my story as a researcher, merged with the stories from the women interviewed.

The women interviewed cared deeply about their experiences and lives, and I too, as I entered their world, became a careful researcher, concerned and caring about them.

How I matured as a Muslim woman, a nurse and researcher

Based on the interviews conducted in the context of the study I believe that the fact that I am a Muslim woman might have had a bearing on the data generation process. Although there are a myriad ways of describing myself in terms of what could have been of relevance within the interview settings (hair and skin colour, gender, nationality) my status as a Muslim seemed to play a role which, however, is difficult to articulate.

By identifying myself as a Muslim woman positioning my work within the interpretive paradigm I am aware that I am situated within a wider religiously political context of health care. Thus, in line with Gadamer (2004) I would like to argue that although this research aims to explore religious and cultural influences on help-seeking behaviour and decision-making in South Asian Muslim women with urinary incontinence, as a Muslim researcher I can only get to understand their views and beliefs. I cannot impose my beliefs or views on them, yet both are as important as each other, the researcher and the participants.

Some ethical consideration

Researcher bias, same background cultural/religious: It is argued that whilst social characteristics such as gender, language, religion and culture are important in determining notions of commonality and difference, a shared experience of cultural and religious influences may effect the research relationship most significantly (Parahoo, 1997). Within the hermeneutical framework, I have considered personal experiences, views and preconceptions as part of the data generated, informing the overall project.

Women researchers on women participants: Some authors in the literature have argued that women should not interview women, however feminists lay emphasis on doing this (Oakley, 1981; Finch, 1984). This can lead to further prejudices as followers of other paradigms question whether participants who have similar socio-demographic characteristics, or who have experiences in common with them, should conduct such interviews. However, I believe this has increased the quality of the data gained, as participants were more willing to address issues of their religion and culture which they had not done before. Some had strong opinions, which they felt needed to be shared, especially in the areas of dominance by their male

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counterparts, and some of their cultural/religious teachings, which they did not agree with.

Use of another language: is it culturally acceptable? It was identified in the process of bringing together a research proposal that not many people from the ethnic minority group would be able to read or understand English. The national statistics for the area of study found 19.4% of this population identified themselves as Muslims, with a majority of these migrating from other countries, where English is not classed as their common language. Urdu was found to be the common language used by many Muslims. All documentation used in this study was translated into Urdu. The documentation was then checked for 'cultural acceptability'. Only then was the documentation finalised and used in the study.

Informed Consent: all participants were informed about the research and what their participation would require. Careful consideration was required as the participants were from specific cultural or ethnic groups. According to Darou et al (1993), ethnic or cultural groups have self-created identities that are unique and very different from the host cultures. Considerations to ensure understanding about the study were important.

Sensitive subject: Urinary incontinence is a difficult and embarrassing subject to discuss in any community. Finding an appropriate manner to discuss without embarrassing people was difficult. A one-to-one session prior to commencing the interviews was provided where all the possible questions and answers about the study were given together with written information.

Vulnerable groups: The use of people from the ethnic minority categories has caused considerable debate in the past (Gil and Bob, 1999; Bhopal, 2001). Ponterotto and Casas (1991) further state issues such as exploitation, community damage, and inaccurate findings have been identified as major concerns with ethnic minority participants. Research should reflect the needs and benefits of participants. Participation in this study was verbally relayed prior to signing the consent forms, I informed participants of their role, and what would happen to the findings, and how, and if they would benefit. I believe that the same religious background helped overcome this consideration. However, this can be identified as another ethical concern, which is discussed above.

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Reassurance: When visiting areas I always carried identification and reassured people about my role and the purpose of the visit.

Gaining the trust and support of professionals in the 'continence services' was paramount as they helped with the identification of Muslim women and potential participants. It was therefore vital to behave in a professional manner and tactfully to deal with situations should they arise. Some community workers were cynical about the whole research process and commented that 'enough research' had been done on the Asian community with no feedback or positive gain to the community, which has been echoed in previous research (Hahn 2003, Wallis 2003; Hussian-Gambles 2004).

I was also aware that researching Muslim women in the study area might cause a barrier for recruiting, as I am from the same geographical area, and I had met many of the participants prior to interviewing through my nursing career. Therefore maintaining confidentiality was very important for the participants and for me. For this reason, continuous reassurance about confidentiality was given.

Honesty: It was essential for me to present myself in a respectable manner. Participants were aware of my professional background as a nurse, as a Muslim woman and as a researcher. Honesty towards the data was also an ethical consideration that I had to consider. I was ignorant of the fact that my role as a Muslim woman may have an impact on the data generated; I only became aware of this through presenting my findings to the MDT urology team.

The findings presented are accurate and true to the data as much as possible.

Summary

The process of reflexivity is difficult to write. It is a process of identifying personal prejudices in relation to the research aims and objectives. According to Davies and Leonard (2004), reflexivity is a personal process of writing. How you write a reflective account has no rules or guidelines to follow (pg 18).

My reflective account was in the form of a journal recording what I achieved or experienced on a particular day and my personal feelings in relation to them. My journal commenced from the first day as a research student until completion of the PhD. Experiences in my journal range from disturbing accounts to achievements.

According to Seale (1999), good practice in relation to reliability and replication can be achieved through an aspect of reflexivity that is showing the audience of research studies as much as possible of the procedures that have led to a particular set of conclusions. This process is central to representation since without this the research would not fulfil the need to acknowledge interpretive research as a socially placed practice (Letherby 2002).

By identifying issues such as reflexivity and making explicit my theoretical position, it was my intention to show that a study which is theoretically positioned within health care studies policies, and providing care, can benefit from theoretical underpinnings, research methods and methodology traditionally applied in health care oriented research. Van Manen (1997) has referred to such a situation as hermeneutic alertness, which occurs in situations where researchers step back and reflect on the meanings of situations rather than accepting their pre-conceptions and interpretations at face value. Therefore, reflexivity became an important aspect of this project.

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Appendix One:

Glossary of terms used throughout thesis

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Asians: Refers to a person whose family originate from India, Pakistan or Bangladesh, or are themselves from the above countries.

Burqa: a head to toe shroud that hides even the feet (Barlas 2002).

Constructionism: Deals with the nature of truth and the inquiry that truth is constructed, through the perceptions, beliefs and ideas of the individual (Crotty, 2003).

Culture: reflects three main elements: values; norms; and artefacts. Values comprise ideas about what in life seems important. They guide the rest of the culture. Norms consist of expectations of how people will behave in different situations. Each culture has different methods, called sanctions, of enforcing its norms. Sanctions vary with the importance of the norm; norms that a society enforces formally have the status of laws. Artefacts, things, or material culture, derive from the culture's values and norms (Helman, 2001).

Decision-making behaviour: how an individual makes a decision about an illness. The consideration of all the risks and benefits of the potential treatment would all be considered prior to seeking help, it also covers areas where individual decides to self-manage.

Detrusor Instability: bladder develops uncontrolled spontaneous contractions.

Disease: a definite pathological process having a characteristic of set signs and symptoms. It may affect the whole body or any of its parts, and its aetiology, pathology and prognosis may be known or unknown (Weller 2001)

Disadvantaged population: Groups of people with diminished capacity to take up opportunities for better health, and who are often denied those opportunities, whether due to internal or external factors (UNI-SOL 1999).

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Asian: Refers to a person whose family originates from India, Pakistan or Bangladesh, or are themselves from the above countries.

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Decision-making pathway: how an individual makes a decision about an illness. The consideration of all the risks and benefits of the potential treatment would all be considered prior to seeking help, it also covers areas where individual decides to self-manage.

Dietary instability: blinder develops uncontrolled spontaneous contractions.

Disease: a definite pathological process having a characteristic of set signs and symptoms. It may affect the whole body or any of its parts, and its aetiology, pathology and prognosis may be known or unknown (Weller 2001)

Disadvantaged population: Groups of people with diminished capacity to take up opportunities for better health, and who are often denied those opportunities, whether due to internal or external factors (UNI-SOL 1999).

ESOL: English for Speakers of Other Languages (ESOL). This is a course, which is targeted at individuals willing to learn the common language of English. Further, for individuals to gain a permanent residency in the United Kingdom, this is a government requirement (Major Immigration Changes in 2006 and beyond).

Epistemology: Deals with the nature of knowledge that is embedded in the theoretical perspective and consequently in the methodology (Crotty, 2003).

Equity: the absence of systematic and potentially remediable differences in one aspect or more aspects of health across populations or population sub-groups defined socially, economically, demographically, or geographically (ISEqH 2001).

Ethnic minority: a group that has different national or cultural traditions from the majority of the population (www.wordnet.princeton.edu).

Ethnocentrism: belief in the superiority of one's own ethnic group (www.wordnet.princeton.edu)

Fatwa: Islamic ruling

Fiqh: Jurisprudence

Hadith: Secondary religious text, which are the narratives purportedly detailing the life and praxis of the Prophet Muhammed (saw) (Barlas, 2002).

Hajj: pilgrimage to the Holy town of Mecca.

Health belief model (HBM): is a psychological model that attempts to explain and predict health behaviours, it focuses on individuals, it explores long and short term health behaviours (Becker 1974). Original developed by Hochbaum, Rosenstock and Kegels in the 1950s.

Health-seeking behaviour: Health-seeking behaviour refers to the sequence of remedial actions that individuals undertake to rectify perceived ill health (Ward et al 1996). Health-seeking behaviour is initiated with symptom definition, whereupon a strategy for treatment action is devised.

ESOL: English for Speakers of Other Languages (ESOL) is a term used to describe the process of teaching English to non-native speakers. It is often used in the context of immigration and integration, where individuals are targeted at individuals willing to learn the language in order to gain a permanent residence status in the United Kingdom.

Etiology: Deals with the cause of a disease or condition. It is a branch of medicine that seeks to understand the factors that lead to the development of a disease, and is often used in the context of public health and epidemiology.

Evaluate: The process of assessing the value or quality of something. It involves comparing a subject against a set of criteria or standards, and is often used in the context of research, education, and business. It is a key component of the scientific method, where the results of an experiment are evaluated against a hypothesis.

Ethnic minority: A group that has different characteristics from the majority of the population (usually the majority of the population).

Ethnocentrism: Belief in the superiority of one's own culture or ethnicity. It is a form of bias that leads to the belief that one's own culture is the most advanced and superior, and is often used to justify discrimination against other groups.

Ethnicity: A social identity based on shared characteristics such as language, culture, and ancestry. It is a complex concept that is often used to describe the relationship between a group of people and their common heritage.

Explain: To make something clear or understandable. It involves providing a detailed account of the reasons behind a particular phenomenon or event, and is often used in the context of research and education.

Hadith: Secondary religious text, which is a collection of sayings and actions of the Prophet Muhammad (peace be upon him) and his companions. It is a key source of Islamic law and is often used to guide the behavior of Muslims.

Hajj: Pilgrimage to the Holy town of Mecca. It is one of the five pillars of Islam and is a mandatory religious duty for all Muslims who are physically and financially able to undertake it.

Health belief model (HBM): A psychological model that explains the relationship between health beliefs and health behavior. It is a key component of the Health Belief Model, which is a widely used framework for understanding health behavior. It focuses on the individual's perception of the benefits and barriers to a particular health behavior, and is often used in the context of health promotion and disease prevention.

Health-seeking behavior: The actions that individuals take to seek medical attention or to prevent illness. It is a key component of the Health Belief Model, and is often used to describe the relationship between health beliefs and health behavior. It is a complex concept that is often used to describe the relationship between a group of people and their common heritage.

Hijab: a head veil that leaves the face uncovered (Barlas 2002).

Ijtihad: independent rational discernment

Illness: a condition marked by pronounced deviation from the normal healthy state (Weller, 2001).

Illness behaviour: the way in which individuals regard the structure and function of their own body, interpret symptoms and seek treatment for their conditions (Weller, 2001).

Inequality in health: the sub-sets of health inequalities that are 'unnecessary, avoidable, unfair and unjust' constitute health inequalities (Whitehead 1992).

Iman: bringing of faith.

Islam: a monotheistic religion founded between 610 and 632 AD by the prophet Muhammed (saw). Derived from an Arabic word meaning 'submission'. Islam literally translated means 'submission to the will of God'.

Interpretivism: Is a perspective, which assumes that all knowledge is subjectively perceived and understood (Crotty, 2003). Interpretivists are concerned with understanding the social reality that people have produced, which consists of meaning and interpretations that individuals give to their actions, other people's actions, social situations and objects (Mason, 2002).

International Consultation on Incontinence (ICI): committee based to identify and provide individuals with appropriate support, with an interest in the symptoms of lower urinary tract.

International Consultation on Incontinence Questionnaire - Lower urinary tract symptoms, quality of life (ICIQ-LUTsqol): Is a self-administered questionnaire designed to assess the impact of urinary incontinence on quality of life (QoL) in women (ICI).

International Consultation on Incontinence Questionnaire - Urinary Incontinence, Short Form (ICIQ-UI SF): is a short questionnaire proposed by the World Health

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(Waller, 2007).
illness: a condition marked by pronounced deviation from the normal healthy state

illness: independent reason, discomfort.

Illness: a head veil that leaves the face uncovered (Bakhtin, 2002).

Organisation, with the aim of providing a clinically easy-to-use set of modules covering all aspects of the assessment of urinary incontinence severity and its impact on quality of life QoL (ICI).

Interviews: a method of data collection used in research settings to gain an in-depth exploration of the given phenomena. Interviews can consist of open and closed ended questions.

Ka'bah: place of worship for Muslims, Mecca.

Lay referral system: consists of a group of people, usually family and friends, to whom the individual describes any symptoms and from whom the patient seeks advice. It is a significant determinant of the decision to seek and to follow medical advice (Freidson, 1970).

Locus of control: measures either external locus of control or internal locus of control. External refers to the belief as individuals we are not in control of our lives, whereas internal refers to having the ability to influence and determine the features that affect your life (Rotter 1954).

Mapi Health Institute: is an international company with an interest in the use of patients-reported and clinical assessment through linguistic validation for appropriate cross-cultural use and interpretation.

Modesty: comprises a set of culturally or religiously determined values that relate to the presentation of the self to others.

Molvi Saab: Health care providers within the Muslim communities who do not have any institutional training in diagnosing and treating illness. Comprises untrained practitioners and faith healers.

Muslim: A follower of Islam is known as a Muslim, which means one who submits.

Namaz: five times daily prayers as ascribed by Allah, that every Muslim is required to fulfil.

Nazar: evil eye

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Namaz: five times daily prayers as prescribed by Allah, that every Muslim is required to fulfil.

Nazar: evil eye.

Nocturia: Nocturia refers to being woken at night by the urge to pass urine.

Pelvic floor exercises: also known as Kegel exercises to help strengthen the pelvic floor muscles. These exercises are normally recommended as a first step to treating symptoms of stress urinary incontinence.

Phenomenology: a qualitative research approach that aims to describe experience as it is lived through by the individual (LoBiondo-Wood and Haber 2002).

Peer Saab: Health care providers within the Muslim communities who do not have any institutional training in diagnosing and treating illness. Comprises untrained practitioners and faith healers.

Professionals: qualified providers who had have some form of training, for example, MBBS doctors, Nurses and specialists.

Quality of Life: the degree of excellence of a characteristic. Different areas all have assigned their own meaning to the term. In broad terms it means the ability to continue with normal life without any restricting or impeding factors of illness or disease.

Questionnaires: are instruments that are designed to gather data from individuals about knowledge, attitudes, beliefs and feelings. These can be condition specific or to test a trait, no matter what type of questionnaire is used, the purpose is to seek information.

Qualitative approach: As stated by Creswell (1998), qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting.

Quran: The holy book for Muslim populations, it provides Muslims guidance and practices that need to be followed by each Muslim in their daily lives.

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Professional: qualified providers who had have some form of training for example MBBS doctors, nurses and specialists.

Provider: health care providers within the Muslim communities who do not have any institutional training in diagnosing and treating illness. Community midwives, practitioners and faith healers.

Phenomenology: a qualitative research approach that aims to describe experience as it is lived through by the individual (Lobelo-Wood and Hader 2005).

Physiotherapy: a qualitative research approach that aims to describe experience as it is lived through by the individual (Lobelo-Wood and Hader 2005).

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Race: group of people of common ancestry with distinguishing physical features, for example skin colour.

Racism: belief in superiority in one race than another. Showing resentment towards members of a different race. Racism is usually believed to be a fear of the unknown, people who look and act differently.

Reflective Communities: Understanding of the complexities of how people explore their relationship to a particular decision or action, how and why they weigh up options as they do (Lash, 2000).

Religion: is commonly defined as a group of beliefs concerning the supernatural, sacred, or divine, and the moral codes, practices, values, institutions and rituals associated with belief (Khattab, 2001). The focus of this study will be the 'Islamic Religion', where the followers are termed as 'Muslims'.

Roza: fasting in the Holy month of Ramadan

Salutogenesis: a concept developed by Antonovsky (1979) to measure coping with life stressors. Found on the opposite end of the pathogenic paradigm.

S.A.W: Sal Allah o alaihe Wasalam: Arabic term used towards the end of the prophet Muhammed name, to show respect. The direct translation 'may the blessings of Allah and peace be upon him'.

Self-care: is any treatment or therapy used without a doctor's prescription or direct recommendation by a health care professional (Stevenson et al 2003). Encompassing the decision not to consult professional health care provider, it involves self-diagnosis by noting symptoms and treatment actions based on the association of symptoms with successful treatment outcomes in the past. Other self-treatment practices include retaining and re-using old medications, purchasing scheduled drugs without prescription, using common remedies, available within the household for what are perceived to be recurring illnesses, or experimenting with medicines recommended by a relative or a friend.

medicines recommended by a physician (Lambert, 1997).

household for what are perceived to be health problems or symptoms (Lambert, 1997).

scheduled drugs without prescription (Lambert, 1997; Lambert, 1997).

treatment practices include religious and spiritual practices (Lambert, 1997).

association of symptoms with religious or spiritual practices (Lambert, 1997).

involves self-diagnosis by using symptoms and spiritual beliefs (Lambert, 1997).

Emphasizing the decision not to seek medical care (Lambert, 1997).

recommendation by a health care professional (Lambert, 1997).

Self-care: is any treatment or care a person receives without a health care professional (Lambert, 1997).

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Muhammad name to show respect (Lambert, 1997; Lambert, 1997).

S.A.W: Sal Allah o alaihe Wasallim Wa alaihe Salaam (Lambert, 1997).

life essence. Found on the outside of the body (Lambert, 1997).

Salutogenesis: a concept developed by Antonovsky (1979) (Lambert, 1997).

Foxt: testing in the Holy month of Ramadan (Lambert, 1997).

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Self-efficacy: can be defined as the extent to which people believe they are competent to confront the challenges in life. Self-efficacy forms part of Bandura (1986) model of social cognition.

Shahdah: witness, belief in one God. 'There is no God but Allah, and Muhammed is his messenger'.

Shariah: The Islamic law

Shia Muslim: a community within the Islamic faith. Shia Muslims believe that Ali is the last prophet sent through Allah.

Sunnah: the way of life prescribed as normative for Muslims on the basis of the teachings and practices of Muhammad and interpretations of the Quran. (www.wordnet.princeton.edu)

Sunni Muslim: a community within the Islamic faith. Sunni Muslims believe that Muhammad is the last prophet sent from Allah.

South Asia: comprises India, Pakistan, Bangladesh, Sri Lanka and Maldives.

South Asian: the term South Asian is often used to indicate people who have originated from Bangladesh, India, Maldives, Nepal, Pakistan and Sri Lanka (Smaje, 1995). For the purpose of this study the term will be used to describe a group of people who either were born in the South Asian countries or are from ethnic minority backgrounds.

Suraths: chapters of the holy Quran

Stress incontinence: Stress incontinence- results from a failure of the urethral sphincter to remain closed when sudden abdominal pressure on the bladder occurs, e.g. during coughing, sneezing or laughing. The weak pelvic floor allows the urethra to descend and the sphincter to open, releasing urine.

Target population: a population or group of individuals that meet the sampling criteria.

Tawheed: bringing of faith and belief in one God.

Tawhīd: phrasing of faith and belief in one God.

chairs.

Territory: a population or group of individuals that meet the sampling

to descend and the sphincter to open, releasing urine.

e.g. during coughing, sneezing or laughing. The weak pelvic floor allows the ureters

Strain incontinence: stress incontinence results from a failure of the urethral

Sūrah: chapters of the holy Qur'an.

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Sunnī: the way of life prescribed as normative for Muslims on the basis of the

last prophet sent through Allah.

Sūfī Muslim: a community within the Islamic faith. Sūfī Muslims believe that All is the

Shari'ah: The Islamic law.

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consistent to confront the challenges in life. Self-efficacy forms part of Bandura

Self-efficacy: can be defined as the extent to which people believe they are

Truth: This term is used throughout this thesis and study. It does not indicate an objective view; rather the term is used to relate to staying true to the narratives and terms used by the participants in this study.

Uff: a dismissive term, to morn.

Urge incontinence: Urge incontinence- results from the contraction of the detrusor muscle of the bladder as if to void, when only small amounts of urine have accumulated in the bladder. This may be caused by overactive detrusor function or by hypersensitivity.

Urinary incontinence (UI): The International Continence Society (ICS) defines urinary incontinence as a 'condition in which involuntary urine loss is a social or hygienic problem and is objectively demonstrable' (Abram et al, 2005).

Urinary tract infection (UTI): the presence of bacteria in the urine (Longmore et al 2001).

Wadu: Cleansing of certain body parts, a ritual carried out by Muslims prior to performing prayers.

WHO: World Health Organisation.

Zakat: One of the pillars of Islam is Zakat. The donation to those who are in need.

Uterus: This term is used throughout this report to refer to the female reproductive organ. The term is used to refer to the organ in its normal position, rather than to refer to it in its abnormal position. The term is used by the participants in this study.

UTI: a descriptive term, to mean:

Urinary incontinence: Urinary incontinence is a condition in which the bladder muscle of the bladder is unable to hold urine in the bladder. This may be caused by a variety of factors, including a weak bladder muscle, a weak pelvic floor, or a weak sphincter. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women.

Urinary incontinence (UI): The information in this section is intended to provide a general overview of the condition. It is not intended to provide a detailed description of the condition. It is not intended to provide a detailed description of the condition. It is not intended to provide a detailed description of the condition.

Urinary tract infection (UTI): The presence of bacteria in the urinary tract. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women.

2001

Wash: Cleaning of certain body parts, such as the hands, with soap and water. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women.

WHO: World Health Organization.

Yeast: One of the pills of yeast is *Saccharomyces cerevisiae*. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women. It is often caused by a weak pelvic floor, which is a common condition in women.

Appendix Two:

Prevalence of Urinary Incontinence Worldwide

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Prevalence of Urinary Incontinence Worldwide

Table 8 Prevalence studies by country

Title and Author(s)	Country	Sample Size	Study Design	Tool Used	Gender	Age Range	Type of UI	Definition of UI in study	Prevalence Rate	Comment
'Incontinence in the Elderly: Prevalence and prognosis' Campbell, Reinken, McCosh (1985)	Gisborne, New Zealand	589	Longitudinal study	Log rank test, including urinary incontinence.	Men and women	65 years and >	Faecal and urinary incontinence	No definition	Women: 4.9% reported SUI Men: 2.6% mixed UI Faecal UI: 31 participants.	Stress UI more common in women. Men more likely to suffer from Faecal incontinence.
'Prevalence of urinary incontinence in patients receiving home care services' Mohide, Pringle, Robertson, Chambers (1988)	Southern Ontario, Canada	2801	One day survey	A two-page pre-coded continence assessment form.	Men and women	16 years to 85 >	Lower Urinary tract symptoms	ICS definition.	Women: 68.5% were incontinent. Men: 31.5% Nocturia: 8% Daytime: 32 % Continuous: 60% Lived alone: 34% Institutionalised: 23%	Age was a predominant factor. Only 41% of the sample reported that UI restricted their activities.
'Parity as a correlate of adult female urinary incontinence prevalence' Foldspang, Mommensen, Lam, Elving (1992)	Aarhus, Denmark	3114 women	Cross sectional longitudinal study	Postal	Female	20 years to 59 years	Non specific UI	No definition provided.	Women: 17.7% During pregnancy: 53.9% Following childbirth: 49.7%	Strong relationship between parity and UI.

<i>The influence of urinary incontinence on the quality of life of elderly women</i> Grimby, Milsom, Molander, Wiklund, Ekelund (1993)	Goteborg, Sweden	6000	Longitudinal study	Nottingham Health profile Questionnaire.	Women	65-83 years	Lower Urinary tract symptoms	ICS definition. As any uncontrolled leakage of urine, regardless of the quantity or the frequency.	Types of UI Stress: 28.3% Urge: 40% Mixed: 31.7%	UI was found to have a far reaching psychological effect. No relationship between severity and the type of UI. Younger women affected more in the emotional category than older.
<i>'Treatment of urinary incontinence in women in general practice: observation study'</i> Seim, Sivertsen, Eriksen, Hunskaar (1996)	Rissa, Norway	105	Observational study with 12 months' follow up	Clinical examination and face to face interviews in consultations.	Women	20 years and over.	Stress UI, Mixed UI and urge UI.	ICS definitions.	Types of UI Stress: 52 Urge: 10 Mixed UI: 42	Urinary incontinence in women can be effectively managed in general practice with simple treatment.
<i>'The prevalence of adult female urinary incontinence in Hong Kong Chinese'</i> Ma (1997)	Shatin District of Hong Kong	362	Community based study	Face to face interviews (non specific)	Women	18 years and above.	Lower urinary tract symptoms.	No definition provided.	Occasional: 34 % Daily: 18.5%	BMI and parity were significant factors for developing UI. UI was not a significant problem, many viewed it as minor.
<i>'Troublesome lower urinary tract symptoms in the community: a prevalence study'</i> Pinnock and Marshall (1997)	Metropolitan and rural communities in South Australia	2890	Interview based prevalence survey.	The omnibus survey, a multiple-user household interview survey and benign prostatic hyperplasia questionnaire. American Urological	Men and women	18 years and above.	Lower Urinary Tract symptoms	No definition provided.	Women: 39% of reported bothersome symptoms. Men: 26% reported symptoms to be bothersome. Frequency: 23% of men, 33% women.	Parlance of UI is reported to be high; however the negative impact is low. Nocturia increased with age.

<p>1. <i>Phragmites australis</i> (Cav.) Trin. ex Steud.</p> <p>2. <i>Scirpus americanus</i> (L.) Pers.</p> <p>3. <i>Eleocharis acicularis</i> (L.) Rostk Schmidt</p> <p>4. <i>Sagittaria arifolia</i> (L.) Link.</p> <p>5. <i>Alisma plantaginifolia</i> (L.) Rostk Schmidt</p> <p>6. <i>Sparganium angustifolium</i> Michx.</p> <p>7. <i>Najas</i> spp.</p> <p>8. <i>Chara</i> spp.</p> <p>9. <i>Hydrocotyle</i> spp.</p> <p>10. <i>Utricularia</i> spp.</p> <p>11. <i>Salvinia</i> spp.</p> <p>12. <i>Wolffia</i> spp.</p> <p>13. <i>Utricularia</i> spp.</p> <p>14. <i>Alisma</i> spp.</p> <p>15. <i>Sparganium</i> spp.</p> <p>16. <i>Scirpus</i> spp.</p> <p>17. <i>Phragmites</i> spp.</p> <p>18. <i>Eleocharis</i> spp.</p> <p>19. <i>Sagittaria</i> spp.</p> <p>20. <i>Najas</i> spp.</p> <p>21. <i>Chara</i> spp.</p> <p>22. <i>Hydrocotyle</i> spp.</p> <p>23. <i>Utricularia</i> spp.</p> <p>24. <i>Salvinia</i> spp.</p> <p>25. <i>Wolffia</i> spp.</p> <p>26. <i>Utricularia</i> spp.</p> <p>27. <i>Alisma</i> spp.</p> <p>28. <i>Sparganium</i> spp.</p> <p>29. <i>Scirpus</i> spp.</p> <p>30. <i>Phragmites</i> spp.</p> <p>31. <i>Eleocharis</i> spp.</p> <p>32. <i>Sagittaria</i> spp.</p> <p>33. <i>Najas</i> spp.</p> <p>34. <i>Chara</i> spp.</p> <p>35. <i>Hydrocotyle</i> spp.</p> <p>36. <i>Utricularia</i> spp.</p> <p>37. <i>Salvinia</i> spp.</p> <p>38. <i>Wolffia</i> spp.</p> <p>39. <i>Utricularia</i> spp.</p> <p>40. <i>Alisma</i> spp.</p> <p>41. <i>Sparganium</i> spp.</p> <p>42. <i>Scirpus</i> spp.</p> <p>43. <i>Phragmites</i> spp.</p> <p>44. <i>Eleocharis</i> spp.</p> <p>45. <i>Sagittaria</i> spp.</p> <p>46. <i>Najas</i> spp.</p> <p>47. <i>Chara</i> spp.</p> <p>48. <i>Hydrocotyle</i> spp.</p> <p>49. <i>Utricularia</i> spp.</p> <p>50. <i>Salvinia</i> spp.</p> <p>51. <i>Wolffia</i> spp.</p> <p>52. <i>Utricularia</i> spp.</p> <p>53. <i>Alisma</i> spp.</p> <p>54. <i>Sparganium</i> spp.</p> <p>55. <i>Scirpus</i> spp.</p> <p>56. <i>Phragmites</i> spp.</p> <p>57. <i>Eleocharis</i> spp.</p> <p>58. <i>Sagittaria</i> spp.</p> <p>59. <i>Najas</i> spp.</p> <p>60. <i>Chara</i> spp.</p> <p>61. <i>Hydrocotyle</i> spp.</p> <p>62. <i>Utricularia</i> spp.</p> <p>63. <i>Salvinia</i> spp.</p> <p>64. <i>Wolffia</i> spp.</p> <p>65. <i>Utricularia</i> spp.</p> <p>66. <i>Alisma</i> spp.</p> <p>67. <i>Sparganium</i> spp.</p> <p>68. <i>Scirpus</i> spp.</p> <p>69. <i>Phragmites</i> spp.</p> <p>70. <i>Eleocharis</i> spp.</p> <p>71. <i>Sagittaria</i> spp.</p> <p>72. <i>Najas</i> spp.</p> <p>73. <i>Chara</i> spp.</p> <p>74. <i>Hydrocotyle</i> spp.</p> <p>75. <i>Utricularia</i> spp.</p> <p>76. <i>Salvinia</i> spp.</p> <p>77. <i>Wolffia</i> spp.</p> <p>78. <i>Utricularia</i> spp.</p> <p>79. <i>Alisma</i> spp.</p> <p>80. <i>Sparganium</i> spp.</p> <p>81. <i>Scirpus</i> spp.</p> <p>82. <i>Phragmites</i> spp.</p> <p>83. <i>Eleocharis</i> spp.</p> <p>84. <i>Sagittaria</i> spp.</p> <p>85. <i>Najas</i> spp.</p> <p>86. <i>Chara</i> spp.</p> <p>87. <i>Hydrocotyle</i> spp.</p> <p>88. <i>Utricularia</i> spp.</p> <p>89. <i>Salvinia</i> spp.</p> <p>90. <i>Wolffia</i> spp.</p> <p>91. <i>Utricularia</i> spp.</p> <p>92. <i>Alisma</i> spp.</p> <p>93. <i>Sparganium</i> spp.</p> <p>94. <i>Scirpus</i> spp.</p> <p>95. <i>Phragmites</i> spp.</p> <p>96. <i>Eleocharis</i> 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<p>275. <i>Sparganium</i> spp.</p> <p>276. <i>Scirpus</i> spp.</p> <p>277. <i>Phragmites</i> spp.</p> <p>278. <i>Eleocharis</i> spp.</p> <p>279. <i>Sagittaria</i> spp.</p> <p>280. <i>Najas</i> spp.</p> <p>281. <i>Chara</i> spp.</p> <p>282. <i>Hydrocotyle</i> spp.</p> <p>283. <i>Utricularia</i> spp.</p> <p>284. <i>Salvinia</i> spp.</p> <p>285. <i>Wolffia</i> spp.</p> <p>286. <i>Utricularia</i> spp.</p> <p>287. <i>Alisma</i> spp.</p> <p>288. <i>Sparganium</i> spp.</p> <p>289. <i>Scirpus</i> spp.</p> <p>290. <i>Phragmites</i> spp.</p> <p>291. <i>Eleocharis</i> spp.</p> <p>292. <i>Sagittaria</i> spp.</p> <p>293. <i>Najas</i> spp.</p> <p>294. <i>Chara</i> spp.</p> <p>295. <i>Hydrocotyle</i> spp.</p> <p>296. <i>Utricularia</i> spp.</p> <p>297. <i>Salvinia</i> spp.</p> <p>298. <i>Wolffia</i> spp.</p> <p>299. <i>Utricularia</i> spp.</p> <p>300. <i>Alisma</i> spp.</p> <p>301. <i>Sparganium</i> spp.</p> <p>302. <i>Scirpus</i> spp.</p> <p>303. <i>Phragmites</i> spp.</p> <p>304. <i>Eleocharis</i> 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'Urinary incontinence in Northern Ireland: a prevalence study' Dolan, Casson, McDonald, Ashe (1999)	Northern Ireland	689		Proceeded by a pilot survey. Longitudinal study.	Association- & BPH questionnaire. Adapted Jolleys (1988) postal questionnaire.	Female	35 to 74 years old	Urinary incontinence none specific	'An involuntary loss of urine that is objectively demonstrable and a social or hygienic problem'.	Daily: 23.4% Occasional: 33.5% Nulliparous: 44% reported UI Parous: 63% reported UI	Increased number of parities increased the likelihood of developing UI. No statistical difference shown among women who carried out pelvic floor exercises.
Urinary incontinence: an unexpected large problem among young females. Results from a population-based study' Hagglund, Olsson, Leppert (1999)	Surahammar, Sweden	3493		Population based study	Postal questionnaires.	Women	18 to 70 years old.	Lower urinary tract.	ICS definition.	Overall: 12% prevalence of UI.	Age was a significant factor for developing UI. UI increased with the number of parities and age.
'The prevalence and bothersomeness of lower urinary tract symptoms in women 40-60 years of age' Moller, Lose, Jorgensen (2000)	One Urban county, Denmark	2860		Ongoing Longitudinal cohort study	Ongoing study. Questionnaire based.	Women.	40 to 60 years old.	Stress UI and Urge UI.	ICS definitions.	Occasional: 63% UI; stress 70%; Continuous Urge 71%; Weekly: 24% Stress UI; Continuous 17%; Urge 18%; Daily: 12% stress UI; Continuous 12%; 9%	The prevalence of incontinence during sexual intercourse is around 2%.
'Determinants of urinary incontinence in a population of young and	Urban area, mid-Sweden	436		Longitudinal survey.	Postal	Female	20 years to 59 years	Remission rate	Not definite definition.	Stress: 15.8% Mixed: 5.3% Urge: 2.1% Non specific: 4.7%	Incontinence was associated with age, parity and smoking, women with UI had a higher likelihood of

middle-age women' Samuelsson, Victor, Svardsudd (2000)														vaginal prolapse.
'The epidemiology of overactive bladder among Females n Asia: a questionnaire survey' Lapitan & Chyeon (2001)	5502					Questionnaire based survey	Lower urinary tract symptoms		Female	18 to 70 years >	Overactive Bladder (OAB)	ICS definition of OAB.	Urgency: 65.4% Frequency: 55.4% Urge: 21.4% Overactive bladder: 51.4%	The study has shown overactive bladder in Asian females is significant. Age and parity known as risk factor. Low treatment seeking in sufferers. Symptoms not troublesome.
'Prevalence rate of urinary incontinence in Community-dwelling elderly individuals' Maggi, Minicuci, Langlois, Pavan, Enzi, Crepaldi (2001)	2398					Community based study	Multi disciplinary questionnaire (MD)		Female: 1531 Male: 867	65 years and over	Urinary incontinence, none specific	'Any involuntary loss of urine'.	Men: 11.2% Women: 21.6% Daily and weekly episodes: 53% of women and 59% of men.	Age increased the likelihood of UI. COPD, hip fractures and Parkinson's all showed a positive link between UI.
'How widespread are the symptoms of an overactive bladder and how are they managed? A population-based prevalence	16 776					Random stratified approach. Population based.	Telephone interviews and some face to face interviews.		Men and women.	40 years and over.	Overactive bladder.	'As the presence of chronic frequency, urgency and urge incontinence to be caused by	Prevalence of OAB by country France: 2.89% Germany: 6.47% Italy: 3.28% Spain: 3.60% Sweden: 0.81% UK: 5.15%	OAB symptoms are highly prevalent.

study' Milsom, Abrams, Cardozo, Thuroffs, Wein (2001)	Norway	27,900	Cross-sectional study	Study is part of the Norwegian EPINCONT study. HUNT 2 survey. Severity index developed by Sandvik et al.	Female	20 years and over.	Lower urinary tract symptoms.	'Any involuntary loss of urine'.	involuntary detrusor contractions.'	Primiparous: 1.6% increase Multiparous: 2.3%.	UI was associated with age and parity. Stress and mixed UI associated with childbearing, but not urge UI.
Age-and Type-Dependent effects of parity on urinary incontinence: The Norwegian EPINCONT study' Rortveit, Yngvild, Hannestad, Kjersti, Daltveit, Hunskaar (2001)											
Prevalence of urinary incontinence in Andorra: impact on women's health' Avellent, Fiter, Cirera, Coll (2003)	Andorra	863	Cross-sectional survey	Self administered questionnaires.	Female	15 years and over.	Lower urinary tract symptoms.	Involuntary urine loss, at present or in the past, that was out of your control.		Stress UI: 20% Regular UI: 17%	Age was a significant factor for developing UI. Parous women more likely to develop UI than non-parous women.
'The prevalence of lower urinary tract symptoms in men and women in four centres. The UrEpik study' Boyle, Robertson, Mazzetta, Keech, Hobbs, Fourcade,	Boxmeer (Netherlands), Auxerre (France), Birmingham (UK), Seoul Republic of Korea.	8769	Cross-sectional survey	International Prostate Symptoms Score (IPSS)	Men and women	49 to 70 years.	Lower urinary tract symptoms.	ICS definition.		France: daily reported LUTs were reported higher in France than in the other countries reported at 17%. UK (Birmingham): Nocturia and daytime urgency was reported the highest, 20% for both men and women.	The prevalence of UI increased with age. No association between smoking and UI.

Kiemeny, Lees (2003)	Five western states of America	1589	Cross-sectional analysis	Mini mental state examination (MMSE) Katz scale and Activities of daily living (IADL), Alcohol abuse screening scale (CAGE)	Female	65 years and older	Urinary incontinence none specific	No definition provided.	Korea (Seoul): Nocturia and daytime urgency was reported more frequently at 17%. Stress: 51.9% Urge: 74.9% Nocturia: 65%	Older women had a relatively low prevalence of UI in comparison to the general population. Factors associated with urge UI: estrogens use, hysterectomy, BMI, diabetes.
'Prevalence and severity of urinary incontinence in Elderly Mexican-American women' Espino, Palmer, Miles, Mouton, Lichtenstein, Kyriakos, Markidis (2003)	France, Germany, Spain and UK	29 500	Cross-sectional survey	Postal survey, adapted from ICI.	Female	>18 year	Urge, stress and mixed	'Any leakage or involuntary loss of urine'. ICS definitions for stress and urge UI.	France: stress 31%; urge: 27%; mixed: 34%. Germany: Stress: 40%; Urge: 16%, Mixed: 38% Spain: Stress: 39%; Urge: 21%; Mixed: 26% UK: Stress: 41%; Urge: 16%; Mixed: 34%	The prevalence of UI in France, Germany and the UK were similar. Under-reporting may be a reason for the low prevalence rate in Spain. Age a significant factor for developing UI.
'The prevalence of urinary incontinence in women in four European countries' Hunksaar, Lose, Sykes, Voss (2004)	Hong Kong	214	Cross sectional study.	Face to face interviews	Male and female	60 years and over	Lower urinary tract symptoms	'All forms of spontaneous, unintentional and unconscious urination.'	Women: 55% reported UI. Men: 25% reported UI. Community residents: 47.2%. Care home residents: 49.2%.	Women reported higher prevalence than men. Age a significant factor.
'The relationship between gender and the psychological impact of urinary incontinence on older people in										

Hong Kong: an exploratory analysis' Lee (2004)	Washington	3536 women	Population based postal survey	Sandvik Index. Incontinence Quality of Life Instrument (I-Patient QoL). Incontinence severity assessment (PISA). PRIME-MD Patient Health Questionnaire World Health Organisation Disability Assessment Schedule II (WHO-DAS II).	Female	30 to 90 years old	Lower urinary tract symptoms.	'Urinary incontinence was defined as leakage of any amount that occurred at least monthly'. ICS definition for stress UI and Urge UI.	Slight UI: 9% Moderate UI: 15% Severe UI: 18% No UI: 58%	Old age, BMI, medical comorbidity, depression, hysterectomy, parity were all significant risk factors for developing UI. White race was more likely to develop UI.
'The impact of urinary incontinence on quality of life among women in Hong Kong' Pang, Leung, Yip Chan, (2005)	Hong Kong	749 women	Longitudinal survey	Chinese version of Urogenital Distress Inventory Short Form (UDI-6). Chinese version of incontinence impact questionnaire short form (IIQ-7).	Female	14 years to > 70 years	Non specific UI	No definition provided.	Stress UI: 13%. Urge UI: 15.5%. 8.5% reported impaired QoL (SUI). 19.8% with urge reported impaired QoL.	Stress UI was the most common UI reported. Women with Urge UI reported higher impact on the QoL.
Prevalence and risk factors of urinary incontinence in Fuzhou Chinese women' Song, Zhang, Song Xu (2005)	China	4684 women.	Postal survey	Bristol Urinary Tract Symptoms.	Female	20 years and over.	Lower urinary tract symptoms.	No definition provided.	Stress UI: 16.6% Urge UI: 10% Mixed UI: 7.7%	Prevalence of UI increased with age. Menopauses, vaginal delivery, Caesarean section, parity, constipation, alcohol consumption, BMI, diabetes BP were

'Incidence of stress urinary incontinence among women in Turkey' Biri, Durukan, Maral, Korucuoglu, Biri, Tyras, Bumin (2006)	Ankara, Turkey	2601	Interview based.	International consultation on incontinence questionnaire-genuine stress incontinence (ICIQ-GSI).	Female	>15 years	Stress incontinence	'Leakage or losing urine during activities'.	16.1% of the population studied have some form of SUI. Age was identified as a statistical risk factor for developing GSI.	Age as a significant factor. Alcohol and smoking were not associated factors.	associated with stress and urge UI.
Population-based survey of urinary incontinence, overactive bladder, and other lower tract urinary symptoms in five countries: results of the EPIC study' Irwin, Milsom, Hunskaar, Reilly, Kopp, Herschorn, Coyne, Kelleher, Hampel, Artibani, Abrams (2006)	France, Germany, Italy, Spain, Sweden, UK.	11 521	Cross-sectional survey	Face to face interviews only in Spain, through the phone.	Male and female.	40 to 64 years.	Over active bladder.	No definition provided.	Nocturia: 48.6% in men; 54.4% women. Storage symptoms: 51.3% men; 59.2% women. Voiding symptoms: 25.7% in men, 19.5% in women. Postmicturition: 16.9% men, 14.2% women.	Age was a risk factor for developing OAB.	

Appendix Three:

Prevalence of Urinary Incontinence in the UK

Appendix Three:

Prevalence of Urinary Incontinence in the UK

Table 9 UK prevalence of Urinary Incontinence

Title Author (s) and date	Location	Sample size	Study Design	Tool used	Gender	Age range	Types of UI	Definition of UI	Prevalence	Comment
'The prevalence, severity and factors associated with urinary incontinence in a random sample of the elderly' Yarnell, Leger (1979)	South Wales	388	Cross sectional survey	A questionnaire on demographic variables, current symptoms, past medical and surgical history and drug usage.	169 males and 219 females	65 years and over	Lower tract urinary symptoms	'loss of bladder control'	Men: 11% Women: 37%	Women more likely to suffer from UI than men. Age an associated factor. Relationship between UI and CVD, prostatic conditions and prolapse.
'Prevalence of urinary incontinence' Thomas, Plymat, Blannin, Meade (1980)	London boroughs (Brent and Harrow).	22 430	Longitudinal survey.	Postal questionnaire; Interviews	Women and men	5 years and over.	Lower urinary tract symptoms	Regular incontinence as two or more episodes occurring in the past month'.	Men: 5-14 years prevalence higher (6.9%), lowest in 25-34 years (0.8%). Women: 55-64 age range prevalence reported highest (11.9%), and lowest 85 years (6.7%).	Age an associated factor. Associated factors, parity, premenopausal and postmenopausal.
'Reported prevalence of urinary incontinence	Leicestershire	833	Cross sectional survey	Postal questionnaire	Women	21 years and over.	Lower urinary tract symptoms.	'Inappropriate of leakage of urine'.	Nulliparous: 31% experienced UI. Parous: 49% experienced UI.	Associated factors included old age and natural part of

<i>in women in a general practice'</i> Jolleys (1988)	Leicestershire.	343	Longitudinal survey	Interviewed using a questionnaire, and abdominal and vaginal examination.	Women	35 years and over.	ICS definition for stress, urge UI.	'Stress incontinence: loss of urine on exertion, without active bladder contraction'. 'Urge incontinence: involuntary loss of urine associated with a strong desire to void'. 'Stress or urge: combination of the above two'.	Postmenopausal: 51%. Premenopausal: 51%. Stress: 63% vs. 73%. Urge: 25% vs. 18%. Mixed: 12% vs. 9%. Kegel exercises reported significant changes and improvement to urinary incontinence. Parity, hysterectomy were associated factor for UI.	ageing.
<i>'Urinary incontinence: prevalence, need for treatment, and effectiveness of intervention by nurse'</i> O'Brien, Austin, Sethi, O'Boyle (1991)	Somerset	5661	RCT, longitudinal survey	Postal questionnaires and randomised controlled trials of assessment and intervention by a nurse followed by either postal or face to face interviews.	515 women and 185 men (included as the met the inclusion criteria).	35 years and over.	Lower urinary tract symptoms	'two or more leaks in any one month'; mild incontinence 'as leaks less than twice a month'	Stress: 55% women; 1% in men. Urge: 10% in women, 20% in women, 75% in men. Mixed: 31% in women, 75% in men. 515 women and 185 men had regular incontinence. UI increased with age. Stress UI was commonest in women. Refusal to seek help.	

'Urinary incontinence in community-analysis of a MORI poll' Brocklehurst (1993)	Great Britain	4007	Cross sectional survey	Interviews and questionnaires.	1883 men, 2124 women.	30 years and over.	Lower urinary tract symptoms	'Bladder problems, leaking, pants, damp pants' A positive answer registered the person as incontinent.	Women: 14% suffered UI Men: 6.6% suffered UI.	Women more likely to consult GP about UI than men. Negative effect on life was common. Causes: parity, age, medical conditions.
'Urinary incontinence in women: its prevalence and its management in a health promotion clinic' Harrison and Memel (1994)	Bristol	314	Longitudinal survey	Postal questionnaires sent out twice and face to face interviews.	Women	20 years and over.	Lower urinary tract symptoms.	No definition provided.	Occasional: 58.2% Weekly: 25.5% Daily: 16.4%.	Incontinence increased between the ages 40 59 years, and decreased 80 years. Parity an associated factor.
'Urinary symptoms and incontinence in women: relationships between occurrence, age and perceived impact' Swinbank, Donovan, Heaume,	British City	2027	Cross sectional survey	Bristol Female Urinary Tract Symptoms Questionnaire (BFLUTS)	Women	19 years and over.	Urgency, stress, urge, incomplete emptying	ICS definition.	Stress: 46% Urge: 435 Urgency: 61% Incomplete emptying: 43%	Associated with age. Nocturia was more troublesome than urge or stress UI. Not perceived to be problematic.

Rogers, James, Yang, Abrams (1999)	Two health care authorities in England.	6139	Longitudinal comparative survey	Structured postal questionnaire; Short form 36 (SF36)	Men and women.	18 years and over.	Lower urinary tract symptoms	'accidentally leaking urine, having pants, needing to go to the toilet frequently or urgently and sometimes not making it to the toilet on time, or using aids and appliances to manage your incontinence or bladder'	HA1 Unable to control: 11%. Nocturia: 3%. Urge: 32% Stress: 52% HA2 Unable to control: 11% Nocturia: 7% Urge: 43% Stress: 46%	Age an associated factor. Self reporting is under-estimated.
'Prevalence of urinary incontinence and its relationship with health status' Roe and Doll (2000)										
'An epidemiologic study to establish the prevalence of urinary symptoms and felt need in the community: the Leicestershire MRC Incontinence Study' Perry, Shaw,	Leicestershire and Rutland.	1304	Cross sectional postal survey	The American Urological Association symptom index for benign prostatic hyperplasia (AUA7) and the ICSmale questionnaire.	Men and women	40 years and over.	Lower urinary tract symptoms.	'Incontinence was regarded as a clinically significant symptom if it occurred several times a month or more often. (Hourly or more often).'	Overall: Incontinence: 79.1% Urgency: 68.6% Frequency: 38.9% Nocturia: 41.8% Men: 59% nocturia. Women: 29% reported UI (none specific).	Age an associated factor. Not bothersome.

Assassa, Dalosso, Williams, Brittain, Mensah, Smith, Clarke, Jagger, Mayne, Castelden, Jones, McGrother (2000)	British City	1540	Cross sectional survey.	Postal questionnaire.	781 men and 740 women	65 years and over.	Lower urinary tract symptoms.	'As having urinary incontinence in the last month, they leaked urine or indicated how much leakage occurred, they protected themselves against leakage, or leakage happened at a defined time.'	Overall prevalence Men: 23% Women: 31%. Frequency Mild: 46% men; 39% women Moderate: 38% men, 35% women Severe: 16% men, 26% women	Age an associated factor. UI greater in women. UI had a negative impact on their quality of life. However a large number of respondents did not seek help in both groups.
'Storage symptoms of the bladder: prevalence and incidence and need for services in the UK' McGrother,	Leicesters hire.	39 602	Cross sectional and longitudinal study	Postal questionnaire adapted from ICI questionnaires.	Men and women.	40 years and over.	Lower urinary tract symptoms.	ICS definition.	Incontinence: severe in 80 +years in women (9.6%). Same age range in men (3.6%0. Urgency: severe in 89+years women (19%)	Age an associated factor.

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Appendix Four:

Race as a risk factor for developing urinary incontinence

Appendix Form

Race as a risk factor for cardiovascular
mortality in the elderly

Appendix four: Race as a Risk factor for developing urinary incontinence

Table 10 Race as a risk factor for developing UI

Title Author	Place of study	Sample size	Study design	Type of UI	Comparison groups	Differences	Comment
'The prevalence of urinary incontinence or prolapsed among white and Hispanic women' Mattox and Bhatia (1996)	Los Angeles, California America	171 women.	Comparative	Stress UI, urge UI and mixed UI.	White and Hispanic women	White: stress 26%; urge 18%, mixed 30%, prolapse 14% Hispanic: stress 41%, urge 9%, mixed 21%, prolapse 26%	Race a factor for UI.
'Racial differences in the structure and function of the stress urinary continence mechanism' Howard, Delancey, Tunn, Aston-Miller (2000)	Michigan, America	35 women.	Comparative	Stress UI	Black women and White women.	21% of Black women had a greater urethral volume. Kegal urethral closure pressure was 29% higher in Blacks. Black women had 24% greater pelvic floor muscle strength.	Nulliparous Black women have greater urethral sphincter capacity than white. Black women less likely to have Stress UI.
'A comparison of urinary incontinence among African American, Asian, Hispanic, and white women'	San Francisco, America	415 women	Comparative	Stress UI, detrusor instability.	47% Hispanic, 23% White, 16% Asian, 14% African-American	42% of African-American women had lower rates of GSI compared to Hispanic (67%) and Whites (59%). African-American (29%) had higher rates of detrusor instability compared to Hispanic (8%), White (15%) or Asian (14%) women.	Asian women tended to present UI at an older age. Hispanic and Asians had similar parities and greater than White and Black women.

Duong and Korn (2001)	America.	315 women	Comparative	Stress UI, detrusor instability, mixed UI	58% African American and 42% Caucasian women.	Stress UI reported by 34% of African American women and 25% of Caucasian women. Detrusor instability reported by 44% by African American women and 47% by Caucasian women.	Race was the most significant factor predictor for stress UI detrusor instability. Race outweighed the established risk factors in the prediction of the physiologic subtype of incontinence.
'Prevalence of urinary incontinence symptoms among black, white, and Hispanic women' Sze, Jones, Ferguson, Barker, Dolezal (2002)	East California, America	2370 women.	Comparative	Stress and Urge UI.	34% Black women, 39% White women, 27% Hispanic women.	Hispanic had a higher parity than White and Black women. 41% of White; 31% Black; 30% Hispanic reported urinary incontinence. 39% White; 27% Black; 24% Hispanic reported stress UI. 19% White; 16% Black; 16% Hispanic reported urge incontinence. 14% Black; 15% White; 9% Hispanic reported mixed UI. 31% Black; 19% White; 25% Hispanic reported frequency. 35% black; 19% White; 26% Hispanic reported nocturia. 30% of Black and Hispanic women reported involuntary urine loss despite having lower prevalence of incontinence than White women.	Race as a risk factor for UI. Young nulliparous Hispanic women appeared to be more likely to report UI. Older parous Black and White women were more likely to have urge and stress UI.
'Urinary incontinence predictors and life impact in ethnically diverse premenopausal women' Sampsel, Harlow, Skumick,	Boston, Chicago, Detroit area, Los Angeles, Newark, Pittsburgh, Oakland, California, America	3258 women.	Comparative	Mild to moderate, severe urinary incontinence.	White, Black, Chinese, Hispanic, Japanese	66% White, 49.5% Black, 50.2% Chinese, 41.5% Hispanic, 52.9% Japanese reported UI. 32.1% reported mixed UI; 14.6% reported moderate UI; 9.9% reported severe UI. Older age, premenopausal status and parity increased the prevalence of UI. 12 had discussed UI with a provider. 50% of women were extremely bothered by the condition, with Hispanic women most likely and Chinese women least likely to report a	All ethnic groups beside whites are more likely to suffer from UI. Black women are less likely to suffer from UI due to higher levels of pelvic floor strength. BMI may subsume the effects of ethnicity on severity.

Brubaker, Bondarenko (2002)	America	194 Women		Comparative	Lower urinary tract symptoms.	African-American and Caucasian	high level of bother.	Prevalence of stress UI than African-American women. Risk factors included HRT use, increased BMI
'Urinary incontinence in primary care: A comparison of older African-American and Caucasian women' Novielli, Simpson, Hua, Diamond, Sultana, Paynter (2003)	East Baltimore, America	Women		Longitudinal Comparative	Lower urinary tract symptoms.	27.7% African American and 72.3% White women.	63% of African-American women reported symptoms of UI compared to 67% of Caucasian women. Caucasian women reported higher	The association between UI and psychological distress may differ depending on ethnicity.
'Urinary incontinence and psychological distress in community-dwelling older African Americans and Whites' Bogner (2004)	Pittsburgh, Pennsylvania, Memphis, Tennessee America	1584 women.		Cross sectional Comparative	Stress and urge UI.	49% Black women and 51% white women.	22% Whites reported UI, compared to 13% of African-American. African Americans with UI were found to have greater rates of psychological distress than these without UI. No association between UI and psychological distress was not found in whites.	Risk factors shared by both types of incontinence, stress and urge, included white race, oral estegron use, and arthritis. White women were three times more likely to suffer from stress and urge UI.
'Urinary incontinence in elderly women: findings from the health and ageing, and body composition study' Jackson, Vittinghoff, Kanaya, Miles, Resnick,								

Kritchevsky, Simonsick, Brown, (2004)	11 countries for Asian countries.	2369 men	Longitudinal Comparative	OAB, frequency, urge and urgency.	206 Chinese, 108 Hong Kong, 361 Indian, 242 Indonesia, 7 Korean, 495 Malaysian, 68 Pakistani, 237 Philippines, 117 Singapore, 407 Taiwan, 121 Thailand.	Overall prevalence of OAB in Asia was 29.9%. China: 30% Hong Kong: 84% India: 14% Indonesia: 14% Korea: 2 people Malaysia: 27% Pakistan: 24% Philippines: 20% Singapore: 29% Taiwan: 23% Thailand: 63%	OAB affects social, psychological, occupational, domestic and physical capabilities of an individual. The prevalence of OAB symptoms in Asian men can be attributed to cultural factors possibly related to learned behaviour. One in three men is affected by OAB most are not severely bothered. Differences may be related to education, social and individual perceptions of symptoms.
'A comparison of urodynamic diagnosis and detrusor muscle function in white and South Indian Asian women' Teo, Yisa, Mayne, Tincello (2005)	England	307 women.	Longitudinal Comparative	Stress UI, Urge UI and mixed UI.	Asian and Caucasian women.	21.7% of Asian women reported stress UI compared to 53% of Caucasian women. Asian women were more likely to suffer from mixed UI 21.7% than Caucasian at 6.9%.	Physiological differences in body composition affected the less likely chance for Asian women developing UI than white. Race as a risk factor.
'Quality of life impact and treatment of urinary incontinence in ethnically diverse older women' Huang, Brown, Kanaya, Creasman,	North California, America	2109 women.	Cross sectional Comparative	Stress UI, urge UI and mixed UI.	20% Black, 20% Latina, 20% Asian, 40% White	Pelvic floor exercise 31% white, 23% Black, 29% Asian, 34% Latina, 10% other (carried out exercises).	No difference in race.

Ragins, van der Eeden, Thom (2006)									
'Difference in prevalence of urinary incontinence by Race/ethnicity' Thom, van der Eeden, Ragins, Wassel-Fyr, Vittinghof, Subak, Brown (2006)	North California, America	3240 women.	Comparative	Stress UI and Urge UI.	White, Hispanic, Asian-American women.	Black, Asian-American women.	White women were more likely to report higher incidence of UI (55%) than other races, Black (15%), Latina (18%), and Asian (19%).	Asian-American women reported low levels of stress and urge symptoms, while white and Hispanic women reported relatively high levels. Black women had less stress incontinence than all other groups, but had the highest prevalence of urge incontinence.	
'Factors associated with prevalent and incident urinary incontinence in a cohort of midlife women: a longitudinal analysis of data' Waetjen, Liao, Johnson, Sampsel, Strenfiedl, Harlow, Gold (2007)	Boston, Massachusetts, Chicago, Illinois, Detroit area, Michigan, Los Angeles, California, Newark, New Jersey, Pittsburgh, Pennsylvania, Oakland, California, America	3302 women.	Longitudinal Comparative	Stress UI, Urge UI and Mixed UI.	African-American, Chinese, Japanese, Hispanic, Caucasian.		Stress UI: African American: 13.1%; Caucasian: 31.8%; Chinese Japanese: 31.1%; Hispanic 21.2%. Urge UI: African American: 11.8%; Caucasian: 7.7%; Chinese: 3.2%; Japanese: 3.8%; Hispanic: 1.4%. Mixed UI: African American: 12.9%; Caucasian: 15.5%; Chinese: 7.2%; Japanese: 6.8%; Hispanic: 4.8%. Other: African American: 1.7%; Caucasian: 2.1%; Chinese: 1.2%; Japanese: 1.1%; Hispanic: 0%.	Parity was significantly associated with prevalent stress and mixed incontinence in Caucasian women. African American women were more likely to report stress and mixed UI.	
'Differences in urinary incontinence between Hispanic and non-Hispanic white women: a population based study'	Colorado, America	741 women	Prospective cohort study Comparative	Stress UI, Mixed UI, Urge UI	250 non-Hispanic white women.	491 white	Stress: 33% Hispanic BCC (50-59 years). 33% Hispanic C (70 years +) 30% BCC (70years +) White, 27% White C (70 years+). Urge: 31% Hispanic BCC (70 years+), 36% C (70 years+) 32% Whites BCC (70 years +), 29% C (70 years +) Mixed: 32% Hispanic C (60-69 years), 26%	Stress UI and mixed UI were more prevalent among Hispanic women than white women. Hispanic women reported UI symptoms more frequently than white women did. Associated factors: ethnic differences	

Daneshgari, Imery, Risendal, Dwyer, Barber, Byers (2008)	Boston, America	2301 Men and 3205 Women.	Population based Comparative	Stress UI, urge UI, Mixed UI.	Black, Hispanic, and White.	<p>Hispanic BCC (60-69 years) 20% Whites BCC (60-69 years), 21% Whites C (70 years +)</p> <p>Any: 45% Hispanic BCC (70 years +), 45% C (60-69 years).</p> <p>45% Whites BCC (70 years +), 35% Whites C (70 years +)</p>	<p>in parity, BMI, diabetes, hysterectomy, bilateral oophorectomy.</p>
'Prevalence of and Risk factors for urine leakage in a racially and ethnically diverse population of adults: the Boston area community health (BACH) survey' Tennstedt, Link, Steers, McKinlay (2008)						<p>Black men: 13.5 % suffer from UI</p> <p>Hispanic men: 2.4% suffer from UI</p> <p>White men : 10.4 %</p> <p>Age range: Black men more likely in the age range 60-79 years old.</p> <p>White men more likely to suffer from UI in the age range of 40-49 years.</p> <p>Hispanic men in the age range of 30-39 years.</p> <p>White women: 67.5% Likely to suffer from UI.</p> <p>Black women: 39.4% likely to suffer fro UI</p> <p>Hispanic women: 49.2% Likely to suffer from UI.</p>	<p>White race more likely to suffer from stress UI and weekly leakage.</p> <p>Rates did not differ in men.</p> <p>Risk factors: heart disease, asthma, depression.</p> <p>The types of and risk factors for urine leakage vary by gender and racial/ethnic groups.</p>

Project Name	Location	Project Type	Project Status	Project Description	Project Manager	Project Sponsor	Project Stakeholders	Project Risks	Project Opportunities
Project A	Location A	Project Type A	Project Status A	Project Description A	Project Manager A	Project Sponsor A	Project Stakeholders A	Project Risks A	Project Opportunities A
Project B	Location B	Project Type B	Project Status B	Project Description B	Project Manager B	Project Sponsor B	Project Stakeholders B	Project Risks B	Project Opportunities B
Project C	Location C	Project Type C	Project Status C	Project Description C	Project Manager C	Project Sponsor C	Project Stakeholders C	Project Risks C	Project Opportunities C
Project D	Location D	Project Type D	Project Status D	Project Description D	Project Manager D	Project Sponsor D	Project Stakeholders D	Project Risks D	Project Opportunities D
Project E	Location E	Project Type E	Project Status E	Project Description E	Project Manager E	Project Sponsor E	Project Stakeholders E	Project Risks E	Project Opportunities E
Project F	Location F	Project Type F	Project Status F	Project Description F	Project Manager F	Project Sponsor F	Project Stakeholders F	Project Risks F	Project Opportunities F
Project G	Location G	Project Type G	Project Status G	Project Description G	Project Manager G	Project Sponsor G	Project Stakeholders G	Project Risks G	Project Opportunities G
Project H	Location H	Project Type H	Project Status H	Project Description H	Project Manager H	Project Sponsor H	Project Stakeholders H	Project Risks H	Project Opportunities H
Project I	Location I	Project Type I	Project Status I	Project Description I	Project Manager I	Project Sponsor I	Project Stakeholders I	Project Risks I	Project Opportunities I
Project J	Location J	Project Type J	Project Status J	Project Description J	Project Manager J	Project Sponsor J	Project Stakeholders J	Project Risks J	Project Opportunities J

Appendix Five:

Demographic data of participants in
the study

Appendix Five:

Demographic data of participants in the study

Table 11 demographic data

South Asian Muslim women who had not sought help

Pseudonym name	Age	Marital status	Medical History	No. of children	Country of birth	No. of people per household	Profession	Identify self as....	Interview length (hr.min)
Fatima	70 years old	Widow	Diabetes, asthma, arthritis, UTI,	Seven	India	6 people in house.	housewife	Indian Muslim	1.10
Aisha	28 years old	Married	Asthma, recurrent thrush and cystitis	Two	England	Four	Admin assistant	British Muslim (Indian)	2.20
Hajira	21 years old	Married	None	One	England	Three	Private tutor	Indian Muslim	0.57
Habiba	50 years old	Married	Asthma, general weakness	Five	India	Five	Kitchen assistant	Indian Muslim	1.20
Rashida	34 years old	Married	None	Two	India	Four	Social worker	Indian Muslim	1.50
Arifa	37 years old	Married	Asthma	Three	India	Six	Office worker	Indian Muslim	0.60
Nadia	37 years old	Married	None	Three	England	Five	Store manager	British Pakistani	1.57
Farzana	31 years old	Married	None	Three	Pakistan	Nine	Housewife	Pakistani Muslim	2.10
Saajida	45 years old	Married	General aches and pains	Five	India	Seven	Kitchen Assistant	Indian Muslim	1.30
Nosheen	42 years old	Married	Asthma	Four	Pakistan	Six	Welfare assistant	Pakistani Muslim	1.15
Tanzeela	37 years old	Married	None	Two	England	Four	Admin assistant	Pakistani Muslim	1.58
Khalsoom	26 years old	Married	None	Two	England	Four	Housewife	Indian Muslim	1.18
Salma	26 years old	Married	None	Two	England	Four	Housewife	Pakistani Muslim	0.50

Zorah	52 years old	Married	Hypertension, Obesity, Sciatica	Seven	Pakistani	Five	Housewife	Pakistani Muslim	1.20
Rukhsana	39 years old	Married	None	Three	England	Five	Shop manager	Indian Muslim	1.68
Noreen	26 years old	Married	Asthma	One	England	Three	Nurse	Pakistani Muslim	1.0
Mariam	34 years old	Married	Angina, Stomach ulcers	Three	India	Seven (including father and mother in law)	Bakery assistant	Indian Muslim	1.36
Shenaz	67 years old	Married	Stomach ulcers, Hypertension, Palpitations, Arthritis	Seven	Pakistan	Ten	Housewife	Pakistani Muslim	0.58
Sobia	58 years old	Widow	None	Six	Pakistan	Four	Housewife	Pakistani Muslim	2.10
Rukhaiya	37 years old	Married	None	Three	India	Six (including mother in law)	Kitchen assistant	Indian Muslim	1.10
Zainab	56 years old	Married	None	Five	India	Five		Indian Muslim	1.60
Sadia	27 years old	Married	None	Two	Pakistan	Four	Housewife	Pakistani Muslim	2.10
Saleema	35 years old	Married	Asthma	Three	India	Five	Manager	Indian Muslim	1.41
Abeeda	57 years old	Married	Asthma, UTI's, Diabetes	Five	India	Five	Housewife	Indian Muslim	1.20
Fozia	26 years old	Married	None	Two	England	Four	Housewife	Pakistani Muslim	2.20
Zeenat	52 years old	Married	Obesity, Hypertension, None	Six	Pakistan	Four	Housewife	Pakistani Muslim	1.57
Zarina	39 years old	Married	None	Three	Indian	Five	Employed	Indian Muslim	1.30

South Asian Muslim women who sought help

Pseudonym names	Age	Marital Status	Medical History	No. of Children	Country of Birth	No. of people per household	Profession	Identify self as ...	Interview length (hr.min)
Farhat	46 years old	Married	Asthma, Diabetes, UI	Five	Pakistan	Eight	Housewife	Pakistani Muslim	2.54

Naila	26 years old	Married	UI	Four	Pakistan	Six	Housewife	Pakistani Muslim	1.34
Shagufta	54 years old	Married	Diabetes, Asthma, Hypertension, Mastectomy, UI	Seven	Pakistan	Seven	Housewife	Pakistani Muslim	1.28
Shahista	54 years old	Married	UI	Three	Pakistan	Three	Housewife	Pakistani Muslim	2.10
Khalida	42 years old	Married	Asthma	Four	India	Three	Kitchen assistant	Indian Muslim	1.50
Neelam	29 years old	Married	UI	Three	India	Five	Housewife	Indian Muslim	1.15
Ghazala	76 years old	Widow	Asthma, Diabetes, Hypertension, UI	Six	Pakistan	Three	Housewife	Pakistani Muslim	0.57
Tayiba	63 years old	Widow	Bed bound, Diabetes, Asthma, TIA's, Angina, UI	Seven	Pakistan	Fourteen	Housewife	Pakistani Muslim	1.00
Nusrat	54 years old	Divorced	Arthritis, Fibroids removed, UI	Four	Pakistan	Four	Housewife	Pakistani Muslim	2.15
Nazia	54 years old	Married	Diabetes, asthma, hypertension, UI	Three	Pakistan	Six	Housewife	Pakistani Muslim	2.10
Roshin	28 years old	Married	Overactive Thyroid, cholestytilis, asthma, UI	Three	England	Five	Housewife	Pakistani Muslim	1.58
Hameeda	46 years old	Married	Depression, angina, diabetes, UI frozen shoulder, oedema	None	Africa	Two	Housewife	Indian Muslim	2.30
Ameena	27 years old	Married	Polycystic ovaries, thyroid function, asthma, UI	One	Africa	Three	Customer Advisor	Indian Muslim (British)	1.20
Sofia	37 years old	Married	None	Two	Pakistan	Four	Housewife	Pakistani Muslim	1.45

Appendix Six:

Information Packs distributed to Participants in the study

Appendix Six:

Information Packs distributed to Participants in the study

Appendix six: information packs for participants

Contents

Advertisement for the study (posters and flyers)

Invitation letter

Participant information sheet

Consent forms

Demographic Questionnaire

Advertisement for the study (posters and flyers): Urdu

Invitation letter: Urdu

Participant information sheet: Urdu

Consent form: Urdu

Demographic questionnaire: Urdu

Appendix six: information packs for participants

Consent

Advertisement for the study (posters and flyers)

Invitation letter

Participant information sheet

Consent forms

Demographic Questionnaire

Advertisement for the study (posters and flyers): Urdu

Invitation letter: Urdu

Participant information sheet: Urdu

Consent form: Urdu

Demographic questionnaire: Urdu

Healthcare is a RIGHT not a SIN!

Should quality of life be impaired by urinary incontinence just because of being a woman? Throughout your life, your body goes through many changes. Your emotional wellbeing is just as important as your physical health!

The Study

You are invited to come along and take part in a study, which will be exploring aspects of women's health, religion and culture. If you would like to make a difference to the women in your community and their health or you would like further information please contact Chandbi on: 07766147165.

Researcher: Chandbi Sange (Staff Nurse).

Healthcare is a RIGHT not a SIN!

Should quality of life be impaired by urinary incontinence just because of being a woman? Throughout your life, your body goes through many changes. Your emotional wellbeing is just as important as your physical health!

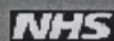
The Study

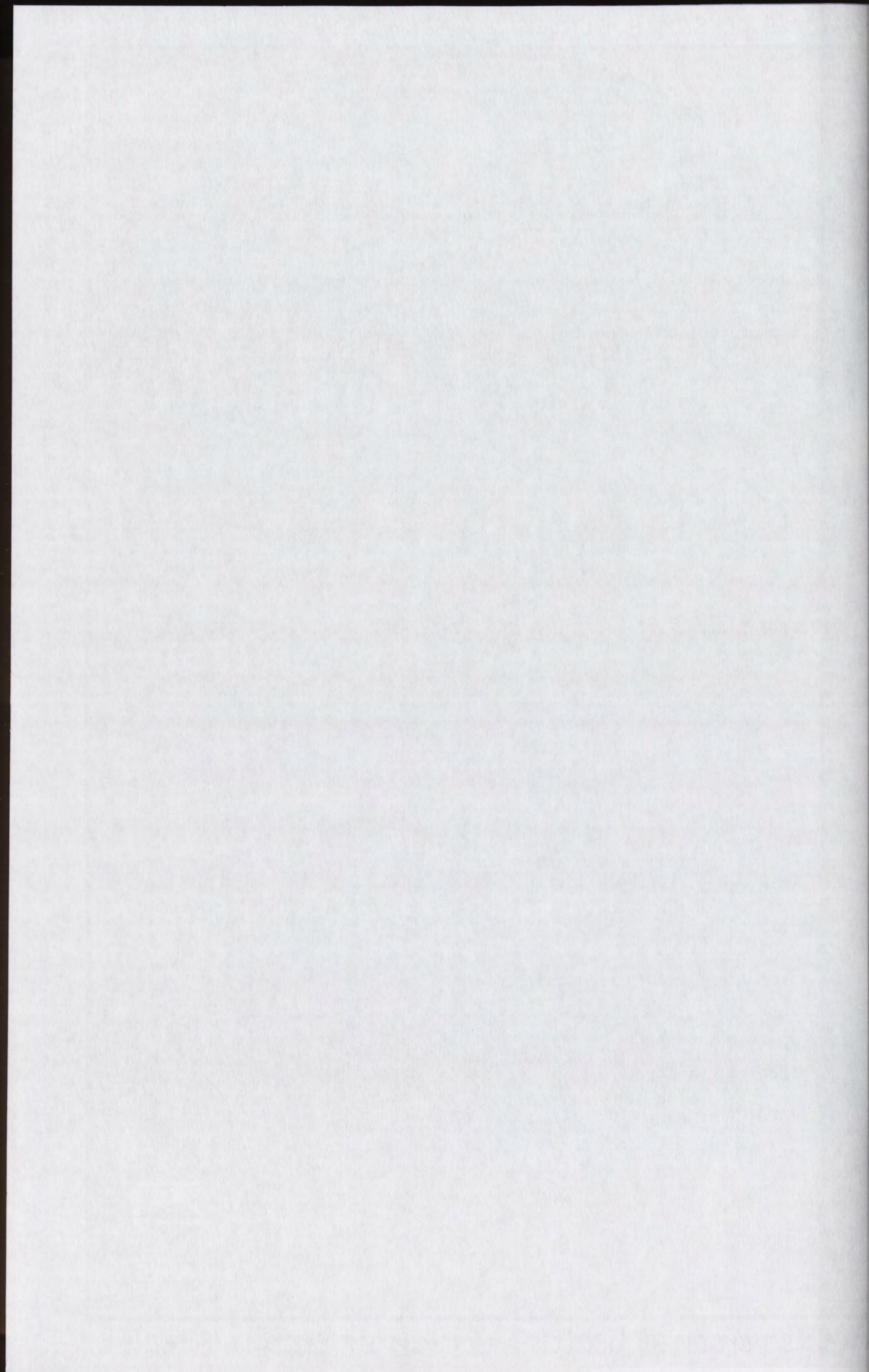
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Researcher: Chandbi Sange (Staff Nurse).



East Lancashire Hospitals
NHS Trust







Date:

Version 2

Invitation Letter

Dear _____

We would like to invite you to take part in a study looking at how religious and cultural beliefs influence South Asian Muslim women seeking help for urinary incontinence.

Taking part in this study will mainly involve being involved in a focus group discussion at the ELHT, which will be facilitated by the researcher. Topics to be covered in the discussion are presented in the 'findings to date' handout in this pack.

Participating in the focus group discussion will help us gain your beliefs and views regarding such a diverse population.

The study is sponsored by the University of Central Lancashire and funded by East Lancashire Hospital Trust, which is part of a student project.

We would like to inform you that a £10 gift voucher will be offered to all participants once the study is complete as a 'thank you' for participating.

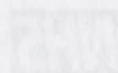
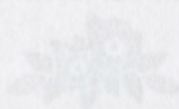
Please read the attached information sheet carefully before deciding if you would like to take part or not, please complete and return the return slip in the stamped enveloped provided.

If you would like any more information about the study please do not hesitate to contact me.

Chandbi Sange
c/o Fatima Utarkar
Mr Hill's Secretary
Tower View Offices
Level 1
Royal Blackburn Hospital
BB2 3HH

Mobile: 07766147165
Email: chandbisange@yahoo.co.uk
Yours sincerely

Chandbi Sange



Date:

Version 2

Invitation Letter

Dear _____

We would like to invite you to take part in a study looking at how religious and cultural beliefs influence South Asian Muslim women seeking help for urinary incontinence.

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If you would like any more information about the study please do not hesitate to contact me.

Chandni Sengupta
c/o Fatima Uskhar
Mr Hill's Secretary
Tower View Offices
Level 1
Royal Birkbeck Hospital
BB2 3HH

Mobile: 07766 47185
Email: chandni.sengupta@lancaster.ac.uk
Yours sincerely

Chandni Sengupta



Version Number: 2

PHASE 1

Participant Information Sheet

Study title

Cultural and Religious influences on help seeking behaviour and decision making in Muslim women with urinary incontinence.

This is an invitation to take part in a research study

This information sheet describes the project and explains what we are asking you do. Before deciding if you would like to take part please take time to read the following information. Please feel free to discuss the study with others. If you have any problems reading or understanding any information, please feel free to contact the researcher, who will go through all the information with you. We can arrange for a link worker to help you to take part if you would like to speak to the researcher in your own language.

What is the purpose of this study?

Problems with urinary incontinence affect many people living in the UK and can have a serious effect on people's daily lives. Many people are reluctant to seek help, perhaps because of embarrassment or because they do not know about help available. Religion and culture may also affect whether or not people seek help from health professionals, and we would like to explore this in our study. We hope that finding out more about this will help health professionals to provide better care for South Asian Muslim women.

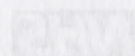
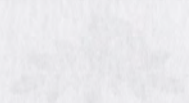
Why have I been chosen?

South Asian Muslim women who are age 18 or over, live in the area of Blackburn and have problems passing water (urinary incontinence) have been chosen to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet and asked to sign a consent form. If you decide to take part and then change your mind, you are free to withdraw at any time and without giving a reason. You can simply tell the researcher that you no longer wish to be part of the study. You may withdraw any comment at any time. A decision to withdraw or a decision not to take part will not affect the standard of care or treatment you receive in any way.

What will happen to me if I take part?



Version Number: 1

PHASE 1

Participant Information Sheet

Study title

Cultural and Religious influences on pain seeking behaviour and decision making in Muslim women with urinary incontinence

This is an invitation to take part in a research study

This information sheet describes the project and explains what we are asking you to do. Before deciding if you would like to take part please take time to read the following information. Please feel free to discuss the study with others. If you have any problems reading or understanding any information, please feel free to contact the researcher who will go through all the information with you. We cannot pay for the extra time to help you to take part if you would like to speak to the researcher in your own language.

What is the purpose of this study?

Problems with urinary incontinence affect many people living in the UK and can have a serious effect on people's daily lives. Many people are reluctant to seek help, perhaps because of embarrassment or because they do not know about help available. Religion and culture may also affect whether or not people seek help from health professionals, and we would like to explore this in our study. We hope that findings out from this will help health professionals to provide better care for South Asian Muslim women.

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What will happen to me if I take part?

You will be invited to take part in an interview. The researcher will arrange this at a time and place of your convenience. This will take between one and two hours depending on the information you feel you would like to share with the researcher. You will be asked if the researcher can tape record the interview. You can ask for the tape to be stopped, replayed or changed at anytime. Following the interview you will be given the opportunity to listen to the recording and will be able to request any part of it to be erased if you wish. All tapes will be erased at the end of the study. You will be able to choose whether the interview is conducted in Urdu or English.

What are the possible disadvantages and risks of taking part?

You will be asked to talk about personal and sensitive issues, which may affect you in some way. If this does happen, the researcher will be able to give you contact details of people who may be able to help you.

What are the possible benefits of taking part?

We cannot promise the study will help you personally, but we hope the information we get will help improve the care that South Asian Muslim women receive.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you experience any problems whilst you are participating in the study, please contact the researcher straight away.

Complaints: If you have a concern about any aspects of this study, you should ask to speak with the researchers who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from Queens Park hospital and Community organisations.

Harm: In the event that something does go wrong and you are harmed during the research study there are no special compensation arrangements. If you are harmed and this is due to the researcher's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs.

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised from it. Data will be collected from you in the form of interviews which will be tape recorded. In the process of tape recording you will be given a number, so no else but the researcher can identify you when analysing the data. The data will be stored in the researcher's locked filing cabinet at the University and only the researcher has access to this. The information received from you will only be used for the purposes of this study.

What will happen to the information I give:

After the interview we will ask you to read through a written version to make sure you are happy with it. Once the study is completed you will receive a report of the study findings.

The researcher will follow the University's Code of Conduct for Research, which currently states that "all primary data as the basis for publications should be securely stored for at least 5 years unless otherwise required by contractual terms or the

guidance of relevant professional bodies in a paper and /or electronic form, as appropriate, after the completion of a research project”.

What will happen to the results of the research study?

The results of the study will be written in a report which will be available in July 2008. This study is part of a student research project.

Expenses and payments:

Participants who take part in the study will be given a gift voucher for £10. This payment will be made after the interview has been conducted and is a way of thanking people for helping with this study.

Who is organising and funding the research:

East Lancashire Hospitals NHS Trust is funding this study. It is being managed by the University of Central Lancashire.

Who has reviewed the study?

This study has been given ethical approval from COREC and has been reviewed by the Cumbria and Lancashire Local Research Ethics Committee.

If you have any concerns or questions about this research study, please contact the researcher.

Chandbi Sange
University of Central Lancashire
Department of Nursing
Preston
PR1 2HE
Mobile: 07766147165
Email: chandbisange@yahoo.co.uk

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BB2 3HH

Thank you very much for taking time to read this information sheet.

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Chandhi Sange	Chandhi Sange
University of Central Lancashire	University of Central Lancashire
Department of Nursing	Department of Nursing
Preston	Preston
PR1 2BE	PR1 2BE
Mobile: 07766147162	Mobile: 07766147162
Email: chandhsange@uclan.ac.uk	Email: chandhsange@uclan.ac.uk
082 3111	082 3111
Royal Blackburn Hospital	Royal Blackburn Hospital
Level 1	Level 1
Tower View Office	Tower View Office
Mr Hill, Secretary	Mr Hill, Secretary
60 Patina Urban	60 Patina Urban
Chandhi Sange	Chandhi Sange

Thank you very much for taking time to read this information sheet.



PHASE 2

Participant Information Sheet

Study title

Cultural and Religious influences on help seeking behaviour and decision making in Muslim women with urinary incontinence.

This is an invitation to take part in a research study

This information sheet describes the project and explains what we are asking you to do. Before deciding if you would like to take part please take time to read the following information. Please feel free to discuss the study with others. If you do not understand the information presented in this information sheet, or you have difficulty reading this sheet, please feel free to contact the researcher, details are provided below.

What is the purpose of this study?

Problems with passing water (urinary incontinence) affect many people living in the UK and can have a serious effect on people's daily lives. Many people are reluctant to seek help, perhaps because of embarrassment or because they do not know about help available. Religion and culture may also affect whether or not people seek help from health professionals, and we would like to explore this in our study. We hope that finding out more about this will help health professionals to provide better care for south Asian Muslim women.

Why have I been chosen?

South Asian Muslim women who are aged 18 or over, live in the area of Blackburn and have problems passing water have been chosen to take part in the study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet and asked to sign a consent form. If you decide to take part and then change your mind, you are free to withdraw at any time and without giving a reason. You can simply tell the researcher that you no longer wish to be part of the study. You may withdraw any comments at any time. A decision to withdraw or a decision not to take part will not affect the standard of care or treatment you receive in any way.

What will happen to me if I take part?

You will be invited to take part in an interview. The researcher will arrange this at a time and place of your convenience. This will take between one and two hours depending on the information you feel you would like to share with the researcher. You will be asked if the researcher can tape record the interview. You can ask for the

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Will my taking part in the study be kept confidential?

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What will happen to the information I give:

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What will happen to the results of the research study?

The results of the study will be written in a report which will be available in July 2008. This study is part of a student research project; therefore the results will be presented at conferences, seminars and finally presented in a thesis.

Expenses and payments:

Participants who take part in the study will be given a gift voucher for £10. This payment will be made after the interview has been conducted and is a way of thanking people for helping with this study.

Who is organising and funding the research:

East Lancashire Hospitals NHS Trust is funding this study. It is being managed by the University of Central Lancashire.

Who has reviewed the study?

This study has been given ethical approval from COREC and has been reviewed by the Cumbria and Lancashire Local Research Ethics Committee.

If you have any concerns or questions about this research study, please contact the researcher:

**Chandbi Sange
University of Central Lancashire
Department of Nursing
Preston
PR1 2HE**

Mobile: 07766147165

Email: chandbisange@yahoo.co.uk

Thank you very much for taking time to read this information sheet.

What will happen to the results of the research study?
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Chandni Sango
University of Central Lancashire
Department of Nursing
Preston
PR1 2HE

Mobile: 07566147162
Email: chandni.sango@ucl.ac.uk

Thank you very much for taking time to read this information sheet.



CONSENT FORM

Version 2

Title of Project: Cultural and religious influences on help seeking behaviour and decision making amongst South Asian Muslim women with urinary incontinence.

Name of Researcher: Chandbi Sange

Please initial box

1. I confirm that I have read and understand the information sheet for the above study.
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that all the information about me recorded for this project will be completely anonymous and will not compromise my confidentiality in any way. If the results of the study are published, it will not be possible to identify information about me. ☐
4. I give permission for the group discussion to be tape recorded. I understand that I can listen to the recording following the discussion and request that any parts be erased if I wish. ☐
5. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Researcher

Date

Signature

When completed, 1 copy for participant; 1 for researcher site file.

Title of Project: Cultural and religious influences on health care decisions making amongst ...
incontinence.

Name of Researcher: ...

1. I confirm that I have read and understand the information for the above study
I have had the opportunity to ask questions and have been given answers to my questions
and have had time to consider my decision.

2. I understand that my participation in this study is voluntary and I agree to participate
to withdraw at any time without giving any reason and without incurring any penalty
cost or legal rights being affected.

3. I understand that all the information I provide will be kept confidential
project will be completely anonymous and no identifying information will be
confidentiality in any way. If it is not possible to keep my information
will not be possible to identify my information.

4. I give permission for the data to be used for the purpose of the study and I understand
that I can listen to the recording, viewing the data and I understand that
any data be used if I wish.

5. I agree to take part in the above study.

Name of Participant: _____
Date: _____
Researcher: _____

When completed, I copy for retention in the research file.



Date: _____

Version No: 2

Demographic Data – About You

Below are some questions about *YOU*. This data will be kept **confidential**. Please fill in the following data, as correctly as possible.

Questions 1 to 7 please tick the **one** which you believe is most appropriate to yourself. Questions 8 to 9 are written answers.

1. Age: ☐ 18-25

☐ 26-35

☐ 36-45

☐ 46-55

☐ 56 and Above

2. Ethnic origin: ☐ Indian

☐ Pakistani

☐ Bangladesh

☐ Other Asian

Please specify _____

3. Religion: ☐ Muslim

☐ Hindu

☐ Christian

☐ Sikh

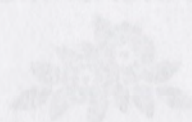
☐ None

4. Country of birth: ☐ UK

☐ India

☐ Pakistan

☐ Bangladesh



Date: _____

Section No: 2

Demographic Data - About You

Below are some questions about YOU. This data will be kept confidential. Please fill in the following data as correctly as possible.

Questions 1 to 7 please tick the one which you believe is most appropriate to yourself. Questions 8 to 9 are written answers.

1. Age:
- | | | | | |
|--------------------------------|--------------------------------|--------------------------------|--------------------------------|---------------------------------------|
| <input type="checkbox"/> 18-25 | <input type="checkbox"/> 26-35 | <input type="checkbox"/> 36-45 | <input type="checkbox"/> 46-55 | <input type="checkbox"/> 56 and Above |
|--------------------------------|--------------------------------|--------------------------------|--------------------------------|---------------------------------------|
2. Ethnic origin:
- | | | | |
|---------------------------------|------------------------------------|--------------------------------------|--------------------------------------|
| <input type="checkbox"/> Indian | <input type="checkbox"/> Pakistani | <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Other Asian |
|---------------------------------|------------------------------------|--------------------------------------|--------------------------------------|
- Please specify: _____

3. Religion:
- | | | | | |
|---------------------------------|--------------------------------|------------------------------------|-------------------------------|-------------------------------|
| <input type="checkbox"/> Muslim | <input type="checkbox"/> Hindu | <input type="checkbox"/> Christian | <input type="checkbox"/> Sikh | <input type="checkbox"/> None |
|---------------------------------|--------------------------------|------------------------------------|-------------------------------|-------------------------------|
4. Country of birth:
- | | | | |
|-----------------------------|--------------------------------|-----------------------------------|-------------------------------------|
| <input type="checkbox"/> UK | <input type="checkbox"/> India | <input type="checkbox"/> Pakistan | <input type="checkbox"/> Bangladesh |
|-----------------------------|--------------------------------|-----------------------------------|-------------------------------------|

5. Marital Status: ☐ Single
☐ Married
☐ Widow
☐ Divorced
☐ Separated

6. Number of Children: ☐ 1-2
☐ 3-4
☐ 5-7
☐ 8+

6. Mode of delivery: Number of Normal Births
Number of Caesarean Births

7. Profession (if any): _____

8. Current place and town of residence: _____

someone else is filling in this questionnaire on your behalf could you please
indicate in a few words the reason for this:

Thank you for completing this questionnaire.

5. Marital Status: ☐ Single ☐ Married ☐ Widowed ☐ Divorced ☐ Separated

6. Number of Children: ☐ 1-2 ☐ 3-4 ☐ 5-7 ☐ 8+

☐ ☐

7. Mode of delivery: Number of Normal Births

☐ ☐

Number of Caesarean Births

8. Profession (if any): _____

9. Current place and town of residence: _____

10. If anyone else is filling in this questionnaire on your behalf could you please indicate in a few words the reason for this: _____

Thank you for completing this questionnaire.

عورتوں کی نجی صحت عورتوں کی نجی صحت عورتوں کی نجی صحت

صحت کی سلامتی ایک حق ہے گناہ نہیں

کیا زندگی کی خصوصیت پیشاب ضبط نہ ہونے سے بگڑ سکتی ہے
کیونکہ صرف اسلئے کہ آپ ایک عورت ہیں۔ تمام زندگی آپ کا
جسم بہت ساری تبدیلیوں سے گزرتا ہے۔ آپ کی جذباتی عافیت اتنی
ہی اہم ہے جتنی آپ کی جسمانی صحت۔

تقریب

آپ کو دعوت دی جاتی ہے کہ آپ انہیں اور اس مطالعے میں حصہ لیں۔ اگر آپ کو اس کے بارے
میں اور جاننا ہے ہم ایک معلوماتی اجلاس منعقد کرنے والے ہیں۔ جو کہ
222 Audley Range (Blackburn) میں (بتاریخ) (بوقت) ہوگا۔

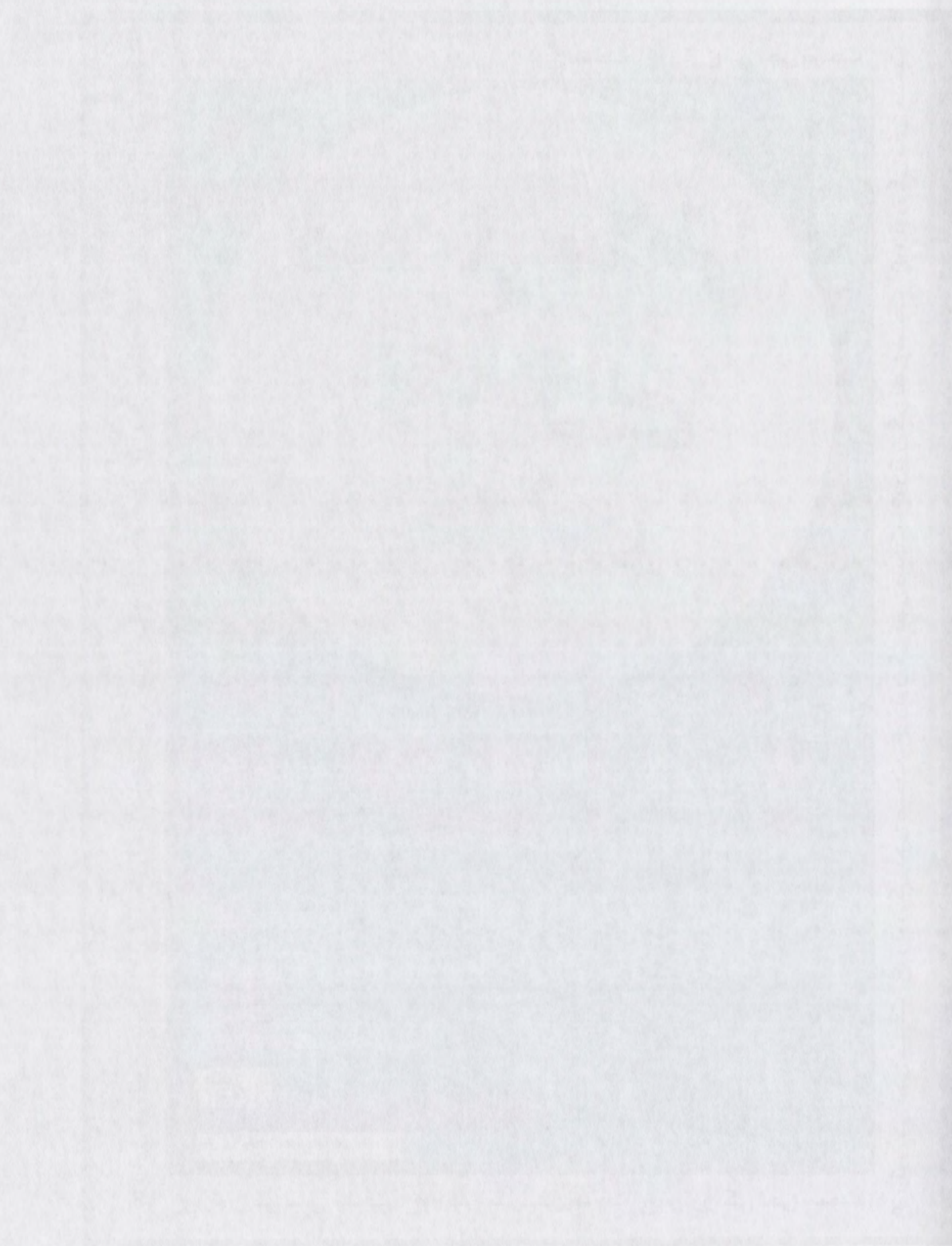
زیادہ تفصیلات حاصل کرنے کیلئے آپ تفتیشکار چاند بی سنگی سے اس تلفون نمبر پر
07766147165 رابطہ کریں۔

uclan

East Lancashire Hospitals NHS Trust

عورتوں کی نجی صحت عورتوں کی نجی صحت عورتوں کی نجی صحت

عورتوں کی نجی صحت عورتوں کی نجی صحت عورتوں کی نجی صحت





تاریخ:

دعوت نامہ قابلیت حصہ لینے والوں کو

محترمہ کا نام

ہم آپ کو بلانا چاہتے ہیں کہ آپ حصہ لیں اس مطالعے میں اور دیکھیں کیسے مذہب اور تہذیب اثر کرتی ہے ساؤتھ ایشین مسلمان عورتوں کو جنہیں پیشاب ضبط نہ ہونے کی تکلیف ہے۔

اس مطالعے میں آپ حصہ لیتے ہیں تو اس میں ضروری شامل ہے تفتیشکار سے آپکا انٹرویو ہونا جو آپ ہی کے ذاتی گھر میں کیا جائے گا۔ تفتیشکار دو دن کے اندر آپ سے رابطہ کرکے پوچھے گا کہ کیا آپ اس میں حصہ لینا چاہتے ہیں۔ اگر آپ دلچسپی رکھتے ہیں حصہ لینے میں، تفتیشکار آپ سے ملاقات کرنے کیلئے وقت کا تعین کرے گا اور مطالعے کے بارے میں تفصیل سے سمجھائے گا اور جواب دے گا آپ کے کسی بھی سوال کا۔

آپ کے حصہ لینے سے ہمیں مدد ملے گی ہمارے علم اور سمجھ داری کو بڑھانے میں کہ کیسے مذہب اور تہذیب اثر کرتے ہیں صحت کی دیکھ بھال کرنے میں، اس کے علاوہ ان پیشہ ور معالج کو بھی مدد ملے گی دیکھ بھال کو بہتر بنانے کی جو ساؤتھ ایشین عورتوں کو دی جاتی ہے۔

اس مطالعے کا امداد یونیورسٹی آف سنٹرل لنکاشائر نے کیا ہے اور اس کا سارا خرچ ایسٹ لنکاشائر اسپتال ٹرسٹ نے کیا ہے، اور یہ طالب علم کی تجویز کا ایک حصہ ہے۔ چاند بی سنگی اسکی تفتیشکار ہے، وہ ایک تربیت یافتہ نرس بھی ہیں۔

اگر آپ اس میں حصہ لینا چاہتے ہیں تو فیصلہ لینے سے پہلے مہربانی فرماکر معلومات نامہ کے ساتھ جڑا ہوا علیحدہ پرچے کو اچھی طرح پڑھیں، اگر آپ کو اس مطالعے کے بارے میں زیادہ معلومات حاصل کرنی ہیں تو بنا کسی ہچکچانے آپ مجھ سے رابطہ کر سکتے ہیں (نیچے تفصیلات کو دیکھیں)۔

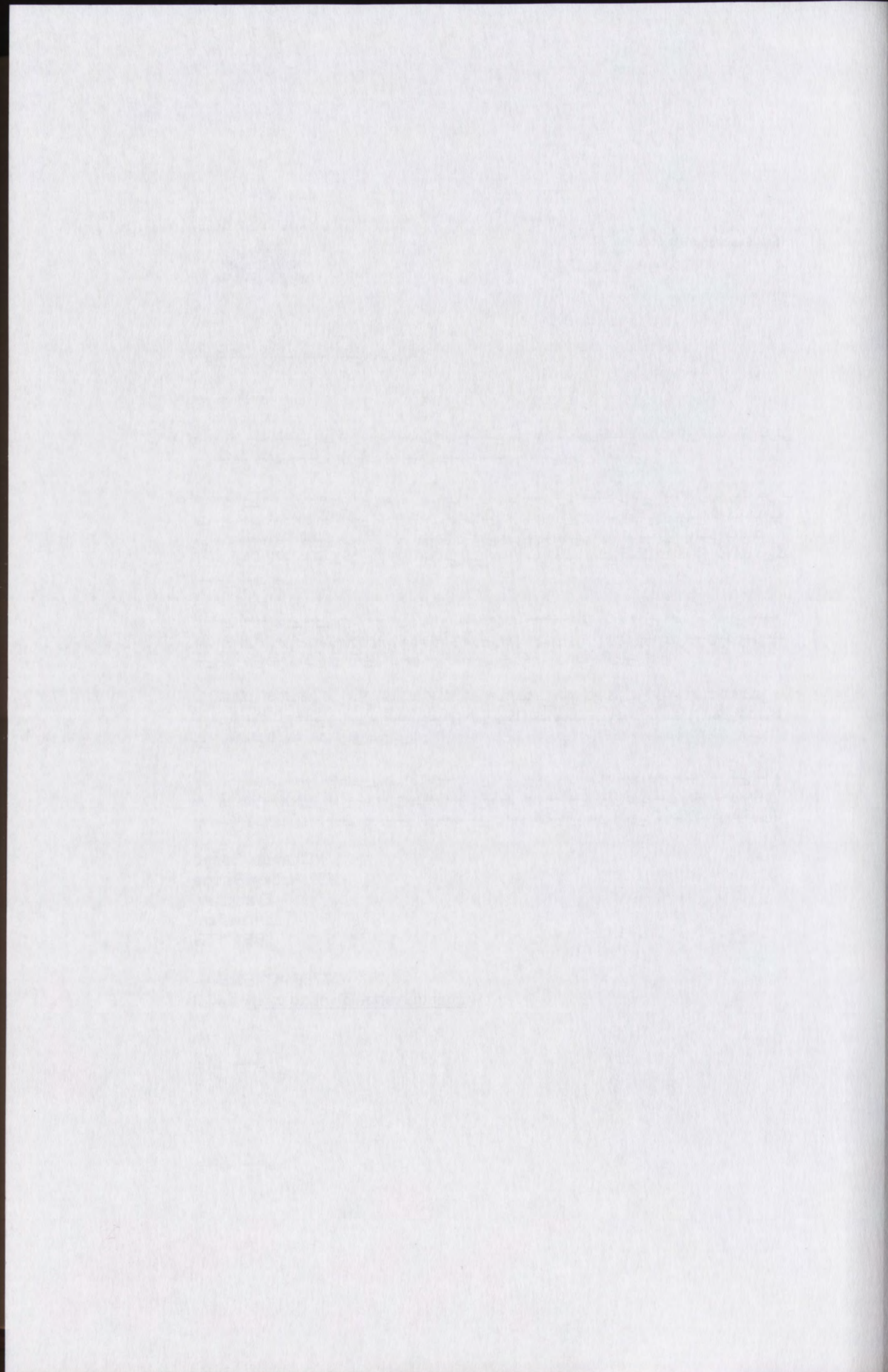
Chandbi Sange
222 Audley Range
Blackburn
Lancashire
BB1 1TG

موبائل: 07766147165

ای میل: chandbisange@yahoo.co.uk

آپکی مخلص

چاند بی سنگی





ترجمہ نمبر: ۲

دعوت نامہ قابلیت حصہ لینے والوں کو

تاریخ:

محترمہ کا نام

NHS مسلسل اپنی خدمات کو بہترین بنانے کے راستے ڈھونڈتی رہتی ہیں، ان میں سے ایک سب سے اچھا طریقہ ہے ان لوگوں کی رائے اور خیال جاننا جو اس خدمات کا استعمال کرتے ہیں۔

اگر آپ نے فیصلہ لیا ہے اس میں حصہ لینے کا تو آپکا انٹرویو کیا جائے گا۔ یہ آپ ہی کے ذاتی گھر میں 1 سے 2 گھنٹے تک چلے گا۔ اس تفتیش میں آپ کا تاثر قابل تعریف ہوگا۔ اس سے ہمیں مدد ملے گی ہماری صحت سے متعلق خدمات کو زیادہ بہتر بنانے میں اور اسے مہیا کرانے میں، ان عورتوں کو جو مسلمان تہذیب سے ہیں۔

اگر آپ سوچتی ہیں اس میں حصہ لینے کو، مہربانی فرمائیے نیچے دی ہوئی معلومات کو اچھی طرح سے پڑھیں جو اس خط کے ساتھ مہیا کی گئی ہیں:

۱. دعوت نامہ

۲. حصہ لینے والوں کا معلوماتی پرچہ

۳. اجازتی فارم

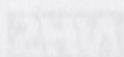
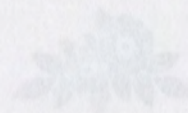
اس تفتیش کے سارے انتظامات یونیورسٹی آف سنٹرل لنکا شائر گائڈ لائنس فار ریسرچ کے مطابق کیا گیا ہے، اور ساتھ میں اس کا معائنہ سنٹرل آفس فار ریسرچ ایٹھکس کمیٹی (COREC) اور ایسٹ لنکاشائر اسپتال ٹرسٹ نے کیا ہے۔ مہربانی فرما کے یقین رکھیں جو معلومات آپ نے مہیا کی ہے اس کا استعمال صرف تفتیش کے عمل میں ہی کیا جائے گا۔

وہ لوگ جو اس مطالعے میں حصہ لینے کا فیصلہ کرتے ہیں، انہیں انکے وقت دینے اور شریک ہونے کے لئے 'بطور شکریہ' 10 پائونڈ کا گفت و اوچر پیش کیا جائے گا۔

اگر آپ کو کچھ بھی دریافت کرنا ہو تو آپ چاند بی سنگی کو ای میل: chandbisange@yahoo.co.uk یا فون 07766147165 کر کے رابطہ کر سکتے ہیں۔

آپکی مخلص

چاند بی سنگی
رسرچ اسٹوڈنٹ/اسٹاف نرس



West Lancashire Hospital
1980 Trust

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ترجمہ نمبر: 1

صورت 1

حصہ لینے والوں کیلئے معلوماتی نامہ

مطالعہ کا خطاب

تہذیب اور مذہبی اختیار پر مدد کی تلاش کے طور طریقے اور فیصلہ لینے میں ان ساؤتھ ایشین عورتوں کو جنہیں پیشاب ضبط نہ ہونے کی تکلیف ہے۔

یہ دعوت نامہ ہے تفتیش میں حصہ لینے کا

یہ معلومات نامہ اس تجویز کے بارے میں بتاتا اور سمجھاتا ہے کہ ہم آپ سے کیا کرنے کیلئے پوچھیں گے۔ اگر آپ اس میں حصہ لینا چاہتے ہیں تو فیصلہ لینے سے پہلے تھوڑا سا وقت نکال کر نیچے دی ہوئی معلومات کو اچھی طرح سے پڑھ لیں۔ اور اگر آپ کو کسی کے ساتھ اس کے بارے میں گفتگو کرنی ہو تو آپ خوشی سے کر سکتے ہیں۔

اس مطالعہ کا مقصد کیا ہے؟

اثر کرتا ہے یوکے میں رہنے والے کتنے افراد کو جو پیشاب ضبط نہ کر پانے کی تکلیف سے مدثر ہیں اور اسکا اہم اثر ان لوگوں کی روز بروز کی زندگی میں ہوتا ہے۔ لیکن بہت سے افراد ہیں جو کہ مدد لینا نہیں چاہتے ہیں شاید کیونکہ وہ بہت شرمندگی محسوس کرتے ہیں اور بعض دفعہ مدد میسر ہے یہ انہیں معلوم ہی نہیں ہوتا ہے۔ ہمارے مطالعے میں یہی ڈھونڈنا چاہتے ہیں کہ شاید کس طرح مذہب اور تہذیب اثر کر سکتا ہے لوگوں کو کہ وہ پیشہ ور معالج سے مدد لیں یا نہیں، ہم امید کرتے ہیں کہ اس کے بارے میں اور معلومات حاصل کرنے سے مدد ملے گی پیشہ ور معالج کو بہتر توجہ مہیا کرانے میں ان ساؤتھ ایشین مسلمان عورتیں کیلئے۔

کیوں مجھے چنا گیا؟

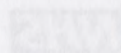
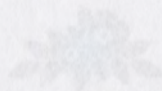
ساؤتھ ایشین مسلمان عورتیں جن کی عمر 18 سال یا پھر اس سے زیادہ ہے، اور وہ بلیک برن کے علاقے میں رہتی ہیں اور انہیں پیشاب ضبط نہ ہونے کی تکلیف ہے تو اسے اس مطالعے میں حصہ لینے کیلئے چنا گیا ہے۔

کیا مجھے اس میں حصہ لینا ہوگا؟

یہ آپ کا فیصلہ ہے کہ آپ کو اس میں حصہ لینا ہے یا نہیں۔ اگر آپ نے ارادہ کیا ہے اس میں حصہ لینے کا تو آپ کو یہ معلوماتی پرچہ دیا جائے گا اور اجازتی فارم پر دستخط کیلئے پوچھا جائے گا۔ اگر آپ نے فیصلہ کیا اس میں حصہ لینے کا اور بعد میں ارادہ بدل دیا، آپ کسی بھی وقت اس سے ہٹ سکتے ہیں بنا کوئی وجہ دئے۔ صرف آپ کو تفتیشکار کو اطلاع کرنا ہوگا کہ آپ اس مطالعے میں اور حصہ لینے کی خواہش نہیں رکھتی ہیں۔ آپ کبھی بھی اپنا تبصرہ دے سکتی ہیں اس سے ہٹ جانے کے فیصلہ یا پھر فیصلہ اس میں حصہ نہ لینے کا۔ اس سے آپ کی توجہ کے معیار اور علاج جو آپ کو مل رہا ہے اس میں کوئی اثر نہیں ہوگا۔

کیا ہوگا اگر میں اس میں حصہ لوں گی؟

آپ کو انٹرویو میں حصہ لینے کیلئے بلایا جائے گا۔ تفتیشکار آپ کی سہولیت کے مطابق وقت اور جگہ کا انتظام کرے گی۔ یہ تقریباً ایک سے دو گھنٹے کے درمیان چلے گا یہ آپ پر منحصر کرتا ہے کہ کونسی



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معلومات آپ محسوس کرتے ہیں تفتیشکار کے ساتھ بانٹتے ہیں۔ آپ سے پوچھا جائیگا کہ کیا تفتیشکار آپ کا انٹرویو رکارڈ کر سکتا ہے۔

آپ ٹیپ کو روکنے، دوبارہ چلانے یا پھر کسی بھی وقت بدلنے کیلئے کہہ سکتے ہیں۔ انٹرویو کے دوران آپ کو موقع دیا جائے گا کہ اس انٹرویو کو سن سکیں اور درخواست کر سکتے ہیں کہ کسی بھی حصے کو اس میں سے مٹائے کیلئے، اگر آپ چاہیں تو۔ مطالعے کے آخر میں ساری ٹیپ کو مٹادیا جائے گا۔ آپ کو چننے کا موقع فراہم کیا جائے گا کہ انٹرویو کا طریقہ اردو میں ہو یا پھر انگریزی میں۔

اس میں حصہ لینے کے ممکنہ کون سے خطرات اور دشواریاں ہیں؟

آپ کی نجی اور کچھ باریک معاملوں پر بات کرنے کیلئے کہا جائے گا، جو شاید آپ کو کسی طرح متاثر کر سکتے ہوں۔ اگر یہ واقعاً ہوتا ہے، تفتیشکار آپ کو چند لوگوں سے رابطہ کرنے کی تفصیلات دے سکتا ہے وہ جو آپکی شاید مدد کر سکیں۔

اس میں حصہ لینے کے ممکنہ فوائد کیا ہیں؟

ہم آپ سے یہ وعدہ نہیں کر سکتے ہیں کہ اس مطالعے سے آپ کو کوئی نجی مدد ملے گی، لیکن ہمیں امید ہے کہ اس سے جو معلومات حاصل ہوگی وہ ہماری مدد کرے گا توجہ کو بہتر کرنے میں جو ان ساؤتھ ایشین عورتوں کو مل رہی ہے۔

کیا ہوگا اگر کوئی مسئلہ درپیش ہوا؟

اگر آپ کو کوئی شکایت ہے کہ مطالعے کے دوران آپکے ساتھ جس طرح پیش آیا گیا، یا پھر شاید ممکن ہے آپکو کوئی نقصان برداشت کرنا پڑا ہو تو اسکو بھی بتانا ہوگا۔ اگر مطالعے کے دوران آپکو کوئی مسئلہ درپیش ہوا تو آپ فوراً تفتیشکار سے رابطہ کر سکتے ہیں۔

شکایتیں: اگر اس مطالعے کے کسی پہلو پر آپکو کوئی سروکار ہو، تو آپ تفتیشکار سے پوچھ سکتے ہیں بات کرنے کیلئے جو ہر ممکن کوشش کریگی آپکے سوالوں کے جواب دینے میں۔ اگر آپ پھر بھی ناخوش ہیں اور خواہش رکھتے ہیں رسمی شکایت کرنے کی، تو آپ NHS کے شکایتی طریقے کے ذریعے کر سکتے ہیں۔ اسکی تفصیلات آپ کو بین پارک اسپتال اور کمیونٹی آرگنائزیشن سے حاصل کر سکتے ہیں۔

نقصان: اس تقریب میں کچھ غلط بھی ہو سکتا ہے اگر مطالعے کے دوران آپکو کوئی نقصان پہنچتا ہے تو اس کے جرمانے کیلئے کوئی خاصی انتظامات نہیں ہے۔ اگر تفتیشکار کی لاپرواہی سے آپکو کچھ نقصان ہوا ہے تو تب شاید آپ اس بنیاد پر جرمانے کیلئے قانونی کارروائی کر سکتے ہیں لیکن قانونی خرچ شاید آپکو ہی دینا پڑے گا۔

کیا مطالعے میں میرا حصہ لینا راز میں رکھا جائے گا؟

ساری معلومات کو آپکے بارے میں اس تفتیش کے دوران اکھٹا کی جائیں گی انہیں پوری طرح رازداری میں رکھا جائے گا۔ آپکے بارے میں کوئی بھی معلومات جو اسپتال/سرجری کے باہر جائیں گی اس پر سے آپ کا نام اور پتہ نکال دیا جائے گا۔ تاکہ اس سے آپکی پہچان نہ ہوسکے۔ انٹرویو کے دوران جو معلومات اکھٹا کی جائیں گی اسے ٹیپ رکارڈ کیا جائیگا، ٹیپ رکارڈنگ کے عمل کے دوران آپکو ایک عدد دیا جائیگا، اسے اور کوئی نہیں صرف تفتیشکار آپکو پہچان پائے گا، جب وہ معلومات کی تفتیش کریگا۔ اس ساری معلومات کو تفتیشکار کے تالا لگے ہوئے یونیورسٹی کے فائلنگ کابینٹ میں رکھا جائے گا اور صرف تفتیشکار ہی اسے حاصل کر سکے گا۔ آپ سے جو معلومات ملی ہے اسے صرف مطالعے کے کام میں ہی استعمال کیا جائے گا۔

کیا ہوگا اس معلومات کا جو میں دونگی؟

ایک بار انٹرویو ہوجانے کے بعد ہم آپکو اس کا لکھا ہوا ترجمہ اچھی طرح پڑھنے کیلئے کہیں گے یہ یقینی بنانے کیلئے کہ آپ اس سے خوش ہیں۔ دفعۃً مطالعے کے ختم ہونے پر آپکو اس مطالعے سے کیا حاصل ہوا ہے اسکا رپورٹ بھیجا جائے گا۔

اس مطالعے کے نتیجے کا کیا ہوگا؟

اس مطالعے کے نتائج کو رپورٹ کی شکل میں لکھا جائے گا جو کہ جولائی 2008 میں دستیاب ہوگا۔

اخراجات اور ادائیگی:

اس مطالعے میں حصہ لینے والوں کو 10 پاؤنڈ کا واچر تحفہ کے طور پر دیا جائے گا۔ اس انٹرویو ہوجانے کے بعد ادا کرنے میں آئیگا یہ ایک طریقہ ہے ان لوگوں کا شکریہ ادا کرنے کا جنہوں نے اس مطالعے میں ہماری مدد کی۔

اس تفتیش کے انتظامات اور امداد کون کر رہا ہے؟
اس مطالعے کا امداد ایسٹ لنکاشائر اسپتال NHS ٹرسٹ کر رہے ہیں۔ اور اسے یونیورسٹی آف سنٹرل لنکاشائر چلا رہی ہے۔

اس مطالعے کا کس نے معائنہ کیا ہے؟
COREC نے اس مطالعہ کو اخلاقی منظوری دی ہے اور اس کا معائنہ کمبریا اور لنکاشائر لوکل ریسرچ ایٹھکس کمیٹی نے کیا ہے۔

اگر آپکو تفتیش کے بارے میں کوئی بھی سوالات ہو تو مہربانی فرماکر تفتیشکار سے رابطہ کیجئے۔

Chandbi Sange
University of Central Lancashire
Department of Nursing
Preston
PR1 2HE
موبائل: 07766147165
ای میل: chandbisange@yahoo.co.uk

آپ کا بہت شکریہ جو آپ نے اس معلوماتی پرچے کو پڑھنے کیلئے وقت نکالا۔



صورت 2

حصہ لینے والوں کیلئے معلوماتی پرچہ

مطالعہ کا خطاب

تہذیب اور مذہبی اختیار پر مدد کی تلاش کے طور طریقے اور فیصلہ لینے میں ان ساؤتھ ایشین عورتوں کو جنہیں پیشاب ضبط نہ ہونے کی تکلیف ہے۔

یہ دعوت نامہ ہے تفتیش میں حصہ لینے کا

یہ معلومات نامہ اس تجویز کے بارے میں بتاتا اور سمجھاتا ہے کہ ہم آپ سے کیا کرنے کیلئے پوچھے گئے۔ اگر آپ اس میں حصہ لینا چاہتے ہیں تو فیصلہ لینے سے پہلے تھوڑا سا وقت نکال کر نیچے دی ہوئی معلومات کو اچھی طرح سے پڑھ لیں۔ اور اگر آپ کو کسی کے ساتھ اس کے بارے میں گفتگو کرنی ہو تو آپ خوشی سے کر سکتے ہیں۔

اس مطالعہ کا مقصد کیا ہے؟

اثر کرتا ہے یو کے میں رہنے والے کتنے افراد کو جنہیں پیشاب جاری رہنے کی تکلیف ہے اور اسکا اہم اثر ان لوگوں کی روز بروز کی زندگی میں ہوتا ہے۔ لیکن بہت سے افراد ہیں جو کہ کسی کی مدد لینا نہیں چاہتے ہیں۔ شاید کیونکہ وہ بہت شرمندگی محسوس کرتے ہیں اور بعض دفعہ مدد میسر ہے یہ انہیں معلوم ہی نہیں ہوتا ہے۔ ہمارے مطالعے میں ہم یہی ڈھونڈنا چاہتے ہیں کہ شاید کس طرح مذہب اور تہذیب اثر کر سکتا ہے لوگوں کو کہ وہ پیشہ ور معالج سے مدد لیں یا نہیں۔ ہم امید کرتے ہیں کہ اس کے بارے میں اور معلومات حاصل کرنے سے مدد ملے گی پیشہ ور معالج کو بہتر توجہ مہیا کرانے میں ان ساؤتھ ایشین مسلمان عورتوں کیلئے۔

کیوں مجھے چنا گیا؟

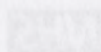
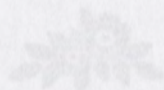
ساؤتھ ایشین مسلمان عورتیں جن کی عمر 18 سال یا پھر اس سے زیادہ ہے اور وہ بلیک برن کے علاقے میں رہتی ہیں اور اسے پیشاب جاری رہنے کی تکلیف ہے تو اسے اس مطالعے میں حصہ لینے کیلئے چنا گیا ہے۔

کیا مجھے اس میں حصہ لینا ہوگا؟

یہ آپ کا فیصلہ ہے کہ آپ کو اس میں حصہ لینا ہے یا نہیں۔ اگر آپ نے ارادہ کیا ہے اس میں حصہ لینے کا تو آپ کو یہ معلوماتی پرچہ دیا جائے گا اور اجازتی فارم پر دستخط کیلئے پوچھا جائیگا۔ اگر آپ نے فیصلہ کیا اس میں حصہ لینے کا اور بعد میں ارادہ بدل دیا آپ کسی بھی وقت اس سے ہٹ سکتی ہیں بنا کوئی وجہ دئے۔ صرف آپ کو تفتیشکار کو اطلاع کرنا ہوگا کہ آپ اس مطالعے میں اور حصہ لینے کی خواہش نہیں رکھتی ہیں۔ آپ کبھی بھی اپنا تبصرہ دے سکتی ہیں اس سے ہٹ جانے کے فیصلے یا پھر فیصلہ اس میں حصہ نہ لینے کا۔ اس سے آپ کی توجہ کے معیار اور علاج جو آپ کو مل رہا ہے اس میں کوئی اثر نہیں ہوگا۔

کیا ہوگا اگر میں اس میں حصہ لونگی؟

آپ کو انٹرویو میں حصہ لینے کیلئے بلایا جائے گا۔ تفتیشکار آپ کی سہولیات کے مطابق وقت اور جگہ کا انتظام کرے گی۔ یہ تقریباً ایک سے دو گھنٹے کے درمیان چلے گا۔ یہ آپ پر منحصر کرتا ہے کہ کونسی معلومات آپ محسوس کرتے ہیں تفتیشکار کے ساتھ بانٹنے میں۔ آپ سے پوچھا جائے گا کہ کیا تفتیشکار آپ کا انٹرویو رکارڈ کر سکتا ہے۔ آپ ٹیپ کو روکنے، دوبارہ چلانے یا پھر کسی بھی وقت بدلنے کیلئے کہہ سکتے ہیں۔ انٹرویو کے دوران آپ کو موقع دیا جائے گا کہ اس انٹرویو کو سن سکیں اور درخواست



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مقدمہ

یہ کتاب انگریزی زبان میں لکھی گئی ہے اور اس میں انگریزی زبان کے قواعد و اصول بیان کیے گئے ہیں۔
اس کتاب کے مصنف نے اس کتاب کو لکھنے میں بہت سی محنت خرچ کی ہے اور اس کتاب کو لکھنے میں بہت سی
مشکلات کا سامنا کیا ہے۔

اس کتاب کے مصنف نے اس کتاب کو لکھنے میں بہت سی محنت خرچ کی ہے اور اس کتاب کو لکھنے میں بہت سی
مشکلات کا سامنا کیا ہے۔

اس کتاب کے مصنف نے اس کتاب کو لکھنے میں بہت سی محنت خرچ کی ہے اور اس کتاب کو لکھنے میں بہت سی
مشکلات کا سامنا کیا ہے۔

اس کتاب کے مصنف نے اس کتاب کو لکھنے میں بہت سی محنت خرچ کی ہے اور اس کتاب کو لکھنے میں بہت سی
مشکلات کا سامنا کیا ہے۔

اس کتاب کے مصنف نے اس کتاب کو لکھنے میں بہت سی محنت خرچ کی ہے اور اس کتاب کو لکھنے میں بہت سی
مشکلات کا سامنا کیا ہے۔

اس کتاب کے مصنف نے اس کتاب کو لکھنے میں بہت سی محنت خرچ کی ہے اور اس کتاب کو لکھنے میں بہت سی
مشکلات کا سامنا کیا ہے۔

کرسکتے ہیں کہ کسی بھی حصہ کو اس میں سے مٹانے کیلئے اگر آپ چاہیں تو مطالعے کے آخر میں ساری ٹیپ کو مٹادیا جائے گا۔ آپ کو چننے کا موقع فراہم کیا جائے گا کہ انٹرویو کا طریقہ اردو میں ہو یا پھر انگریزی میں۔

اس میں حصہ لینے کے ممکن کون سے خطرات اور دشواریاں ہیں؟

آپ کی نجی اور کچھ باریک معاملوں پر بات کرنے کیلئے آپکو کہا جائے گا، جو شاید آپکو کسی طرح مدثر کرسکتے ہوں۔ اگر یہ واقعاً ہوتا ہے، تفتیشکار آپ کو چند لوگوں سے رابطہ کرنے کیلئے تفصیلات دے سکتا ہے وہ جو آپکی شاید مدد کرسکے۔

اس میں حصہ لینے کے ممکن فوائد کیا ہیں؟

ہم آپ سے یہ وعدہ نہیں کرسکتے ہیں کہ اس مطالعے سے آپکو کوئی نجی مدد ملے گی، لیکن ہمیں امید ہے کہ اس سے جو معلومات حاصل ہوگی وہ ہماری مدد کرے گا توجہ کو بہتر کرنے میں جو ان ساؤتھ ایشین مسلمان عورتوں کو مل رہی ہے۔

اگر کوئی مسئلہ درپیش ہوتا تو کیا ہوگا؟

اگر آپکو کوئی شکایت ہے کہ مطالعے کے دوران آپکے ساتھ جس طرح پیش آیا گیا یا پھر شاید ممکن ہے آپکو کوئی نقصان برداشت کرنا پڑا ہو تو اسکو بھی بتانا ہوگا۔ اگر مطالعے کے دوران آپکو کوئی مسئلہ درپیش ہوا تو آپ فوراً تفتیشکار سے رابطہ کرسکتے ہیں۔
شکایتیں: اگر اس مطالعے کے کسی پہلو پر آپکو کوئی سروکار ہو تو آپ تفتیشکار سے پوچھ سکتے ہیں، بات کرنے کیلئے جو ہر ممکن کوشش کرے گی آپکے سوالوں کے جواب دینے میں۔ اگر آپ پھر بھی ناخوش ہیں اور خواہش رکھتے ہیں رسمی شکایت کرنے کی، تو NHS کے شکایتی طریقے کے ذریعے کرسکتے ہیں۔ اسکی تفصیلات آپ کو کوین پارک اسپتال اور کمیونٹی آرگنائزیشن سے حاصل کرسکتے ہیں۔

نقصان: اس تقریب میں کچھ غلط بھی ہوسکتا ہے اگر مطالعے کے دوران آپکو کوئی نقصان پہنچا ہے تو اس کے جرمانے کیلئے کوئی خاص انتظامات نہیں ہیں۔ اگر تفتیشکار کی لاپرواہی سے آپکو کچھ نقصان ہوا ہے تو تب شاید آپ اس بنیاد پر جرمانے کیلئے قانونی کارروائی کرسکتے ہیں لیکن قانونی خرچ شاید آپکو ہی دینا پڑے گا۔

کیا مطالعے میں میرا حصہ لینا راز میں رکھا جائیگا؟

ساری معلومات جو آپکے بارے میں اس تفتیش کے دوران اکھٹا کی جائیں گی انہیں پوری طرح راز میں رکھا جائے گا۔ آپکے بارے میں کوئی بھی معلومات جو اسپتال/سرجری کے باہر جانے گی اس پر سے آپ کا نام اور پتہ نکال دیا جائے گا تاکہ اس سے آپکی پہچان نہ ہوسکے۔ انٹرویو کے دوران آپ سے جو معلومات اکھٹا کی جائے گی اسے ٹیپ رکارڈ کیا جائے گا۔ ٹیپ رکارڈنگ کے عمل کے دوران آپکو ایک عدد دیا جائے گا اسے اور کوئی نہیں صرف تفتیشکار آپکو پہچان پائے گا۔ جب وہ معلومات کی تفتیش کرے گا۔ اس سے ساری معلومات کو تفتیشکار کے تالا لگے ہوئے یونیورسٹی کی الماری میں رکھا جائے گا اور صرف تفتیشکار ہی اسے حاصل کرسکے گا، آپ سے جو معلومات ملی ہے اسے صرف مطالعے کے کام میں ہی استعمال کیا جائے گا۔

کیا ہوگا ان معلومات کا جنہیں میں دونگی؟

ایک بار انٹرویو ہو جانے کے بعد ہم آپکو اس کا لکھا ہوا ترجمہ اچھی طرح پڑھنے کیلئے کہیں گے یہ یقینی بنانے کیلئے کہ آپ اس سے خوش ہیں۔ دفعۃً مطالعے کے ختم ہونے پر آپکو اس مطالعے سے کیا حاصل ہوا اسکی رپورٹ بھیجی جائے گی۔

اس مطالعے کے نتیجے کا کیا ہوگا؟

اس مطالعے کے نتائج کو رپورٹ کی شکل میں لکھا جائے گا جو کہ جولائی 2008 میں دستیاب ہوگا۔

اخراجات اور ادائیگی:

اس مطالعے میں حصہ لینے والوں کو 10 پاؤنڈ کا واؤچر تحفہ کے طور پر دیا جائے گا۔ اسے انٹرویو ہو جانے کے بعد ادا کرنے میں آنے گا یہ ایک طریقہ ہے ان لوگوں کا شکریہ ادا کرنے کا جنہوں نے اس مطالعے میں ہماری مدد کی۔

اس تفتیش کے انتظامات اور امداد کون کر رہا ہے:
اس مطالعے کا امداد ایسٹ لنکاشائر اسپتال NHS ٹرسٹ کر رہی ہیں۔ اور اسے یونیورسٹی آف سنٹرل لنکاشائر چلا رہی ہے۔

اس مطالعے کا کس نے معائنہ کیا ہے؟
COREC نے اس مطالعے کو اخلاقی منظوری دی ہے اور اس کا معائنہ کمبریا اور لنکاشائر لوکل ریسرچ ایتھکس کمیٹی نے کیا ہے۔

اگر آپکو اس تفتیش کے بارے میں کوئی بھی سوالات ہوتو مہربانی فرماکہ تفتیشکار سے رابطہ کیجئے:

Chandbi Sange
University of Central Lancashire
Department of Nursing
Preston
PR1 2HE

موبائل: 07766147165
ای میل: chandbisange@yahoo.co.uk

آپ کا بہت شکریہ جو آپ نے اس معلوماتی پرچے کو پڑھنے کیلئے وقت نکالا۔

1. The first part of the document is a list of names and addresses of the members of the committee.

2. The second part of the document is a list of names and addresses of the members of the committee.

3. The third part of the document is a list of names and addresses of the members of the committee.

4. The fourth part of the document is a list of names and addresses of the members of the committee.

5. The fifth part of the document is a list of names and addresses of the members of the committee.

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10. The tenth part of the document is a list of names and addresses of the members of the committee.

11. The eleventh part of the document is a list of names and addresses of the members of the committee.

12. The twelfth part of the document is a list of names and addresses of the members of the committee.

13. The thirteenth part of the document is a list of names and addresses of the members of the committee.

14. The fourteenth part of the document is a list of names and addresses of the members of the committee.



اجازت نامہ

تجویز کا خطاب: تہذیب اور مذہبی اختیار پر مدد کی تلاش کے طور طریقہ اور فیصلہ لینے میں ان ساؤتھ ایشین مسلم عورتیں جنہیں پیشاب ضبط نہ ہونے کی تکلیف ہے۔

تفتیش کار کا نام: چاند بی سنگی

مہربانی کر کے اس خانے میں دستخط کریں

- (1) میں تصدیق کرتی ہوں کہ میں نے تاریخ (ترجمہ.....) اس معلوماتی پرچہ جو اوپر دئے ہوئے مطالعہ کیلئے ہے کو اچھی طرح پڑھ اور سمجھ لیا ہے۔ یہ موقع دیا گیا تھا کہ میں توجہ دوں اس معلومات کو اور پوچھے ہوئے سوالوں کے جوابات سے میں مطمئن ہوں۔

- (2) میں یہ اچھی طرح سے سمجھتی ہوں کہ میں اپنی مرضی سے اس میں حصہ لے رہی ہوں، اور میں کسی بھی وقت ہٹ سکتی ہوں بغیر کسی وجہ دئے ہوئے اور اس سے نہ میرے طبی اور قانونی حق کو اثر پہنچے گا۔

- (3) میں سمجھتی ہوں کہ میری ساری معلومات جو اس تجویز کے مطابق رکارڈڈ ہے اسے پوری طرح سے نام رکھا جائے گا ساتھ میں رازداری میں کسی طرح کا سمجھوتا نہیں کیا جائے گا۔ اگر اس مطالعے کے نتیجے اعلان کرنے میں آئیں تو میری پہچان کی معلومات حاصل کرنا مکمل نہیں ہوگا۔

- (4) میں سمجھتی ہوں کہ اس مطالعے کے دوران کوئی بھی مناسب حصہ میری طبی نوٹس اور اکٹھا کی ہوئی جانکاری کو، شاید منتظمانہ ٹیم سے کوئی ذمہ دار شخص اسکو دیکھ سکتا ہے، یہ پھر NHS ٹرسٹ، جہاں یہ مناسب ہو میرا اس تفتیش میں حصہ لینا۔ میں اجازت دیتی ہوں اس شخص کو جو میرے رکارڈ کو حاصل کرسکے۔

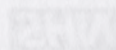
- (5) میں اجازت دیتی ہوں اپنے انٹرویو کو رکارڈ کرنے کی۔ میں جانتی ہوں کہ میں اپنا رکارڈ کیا ہوا انٹرویو سن سکتی ہوں اور اگر میں چاہوں تو درخواست کرسکتی ہوں کچھ حصوں کو مٹانے کی۔

- (6) میں اوپر دینے ہوئے مطالعے میں حصہ لینے کا اقرار کرتی ہوں۔

دستخط	تاریخ	حصہ لینے والے کا نام
دستخط	تاریخ	اجازت لینے والے شخص کا نام (اگر تفتیشکار سے الگ ہو)
دستخط	تاریخ	تفتیشکار



Page 1 of 1



WJEC
Welsh Joint Education Committee

Mathematics

The following questions are to be answered in the spaces provided. You must show all your working and state the units of any answers.

1. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

2. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

3. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

4. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

5. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

6. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

7. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

8. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

9. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

10.

11.

12. A car starts from rest and accelerates uniformly to a speed of 30 m/s in 10 s. Calculate the distance travelled by the car during this time.

13.

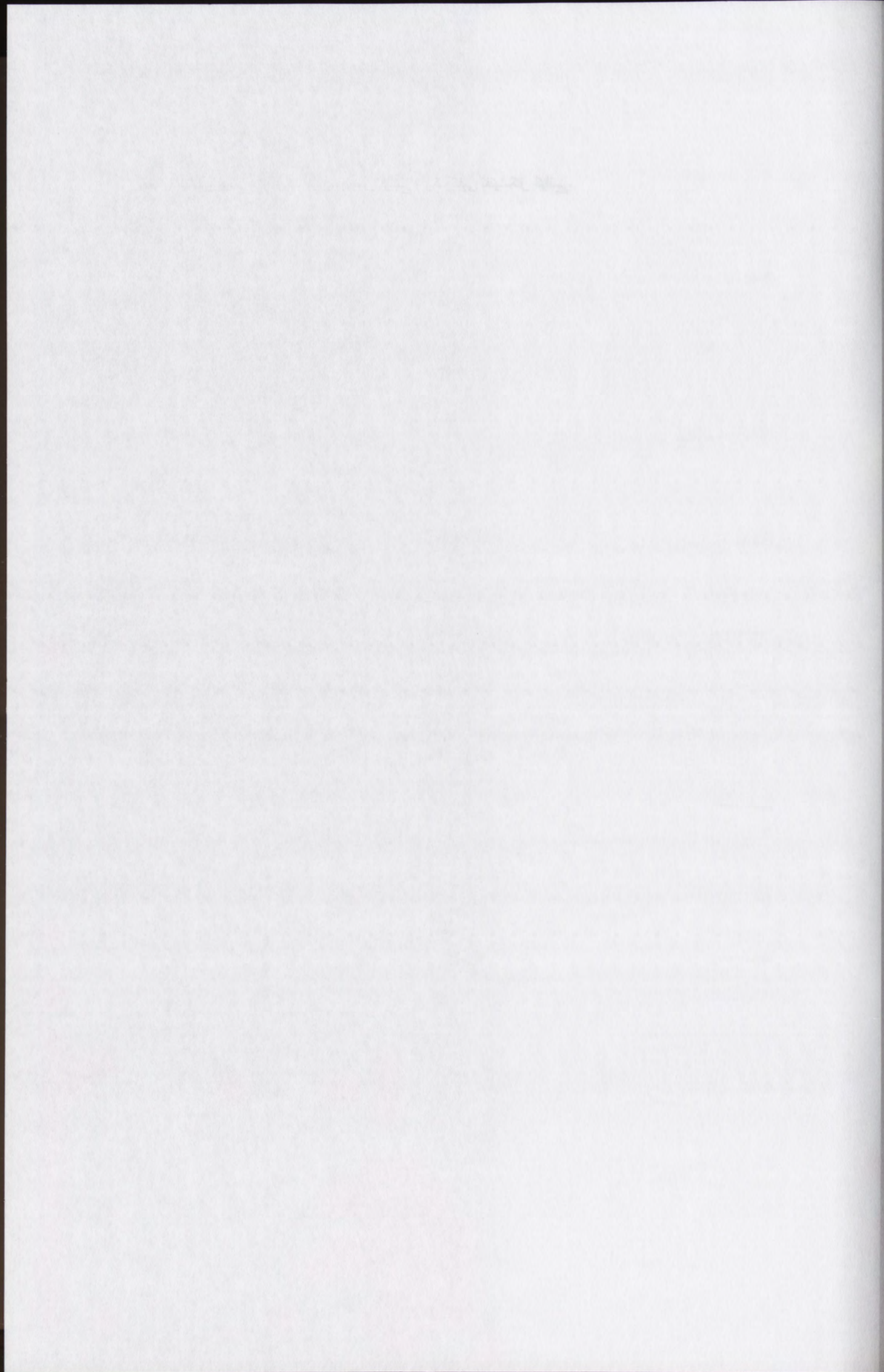
14.

15.

16.

17.

جب یہ ختم ہو جائے، تو ایک کاپی مریض کیلئے؛ ایک کاپی تفتیشکار کیلئے۔



تاریخ: _____

ترجمہ نمبر: 2

آبادی کا اعداد و شمار - آپکے بارے میں

آپکے بارے میں کچھ سوالات ہیں۔ ان معلومات کو پوری طرح راز میں رکھا جائے گا۔ مہربانی فرما کر نیچے دئے ہوئے سوالوں کے صحیح جوابات دیجئے۔

سوال 1 سے 7 آپ ان میں سے کسی ایک کو چن سکتے ہیں جو آپکی مطابق سب سے مناسب ہے۔ سوال 8 سے 9 تک لکھے ہوئے جواب ہیں۔

1. عمر:	<input type="checkbox"/> 18-25	2. آپ کس ملک سے ہیں:	<input type="checkbox"/> ہندوستانی
	<input type="checkbox"/> 26-35		<input type="checkbox"/> پاکستانی
	<input type="checkbox"/> 36-45		<input type="checkbox"/> بنگلہ دیشی
	<input type="checkbox"/> 46-55		<input type="checkbox"/> دوسرے ایشیائی
	<input type="checkbox"/> 56 اور اس سے زیادہ	براہ مہربانی نشان دہی کریں	_____

3. مذہب:	<input type="checkbox"/> مسلم	4. پیدائش کی جگہ:	<input type="checkbox"/> انگلینڈ
	<input type="checkbox"/> ہندو		<input type="checkbox"/> انڈیا
	<input type="checkbox"/> عیسائی		<input type="checkbox"/> پاکستانی
	<input type="checkbox"/> سکھ		<input type="checkbox"/> بنگلہ دیش
	<input type="checkbox"/> کوئی نہیں		

5. ازدواجی درجہ:	<input type="checkbox"/> اکیلا	6. بچوں کی تعداد:	<input type="checkbox"/> 1-2
	<input type="checkbox"/> شادی شدہ		<input type="checkbox"/> 3-4
	<input type="checkbox"/> بیوہ		<input type="checkbox"/> 5-7
	<input type="checkbox"/> طلاق شدہ		<input type="checkbox"/> 8+
	<input type="checkbox"/> علیحدہ		

5. روزنامه: _____

روزنامه: _____

روزنامه: _____

روزنامه: _____

روزنامه: _____

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روزنامه: _____

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روزنامه: _____

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25-85

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روزنامه: _____

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25-89

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روزنامه: _____

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25-94

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7. پیدائش کا طریقہ: قدرتی پیدائش کی تعداد

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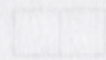
پیدائش آپریشن کے ذریعے

8. پیشہ (اگر کوئی ہو):

9. کونسا قصبہ اور موجودہ گھر کا پتہ:

اگر کوئی یہ سوال نامہ آپ کیلئے بھر رہا ہے تو مہربانی فرما کر چند الفاظ میں اسکی وجہ ظاہر کیجئے:

شکریہ اس سوال نامہ کو مکمل کرنے کیلئے۔



بسم الله الرحمن الرحيم

Appendix Seven:

Advertisement for the Study

Appendix Seven:

Advertisement for the Study

Appendix seven: Advertisement for the study

Contents

- a. Posters and Flyers for the study – English
- b. Posters and Flyers for the study – Urdu

Contents

a. Posters and Flyers for the study - English

b. Posters and Flyers for the study - Urdu

Healthcare is a RIGHT not a SIN!

Should quality of life be impaired by urinary incontinence just because of being a woman? Throughout your life, your body goes through many changes. Your emotional wellbeing is just as important as your physical health!

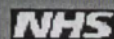
The Study

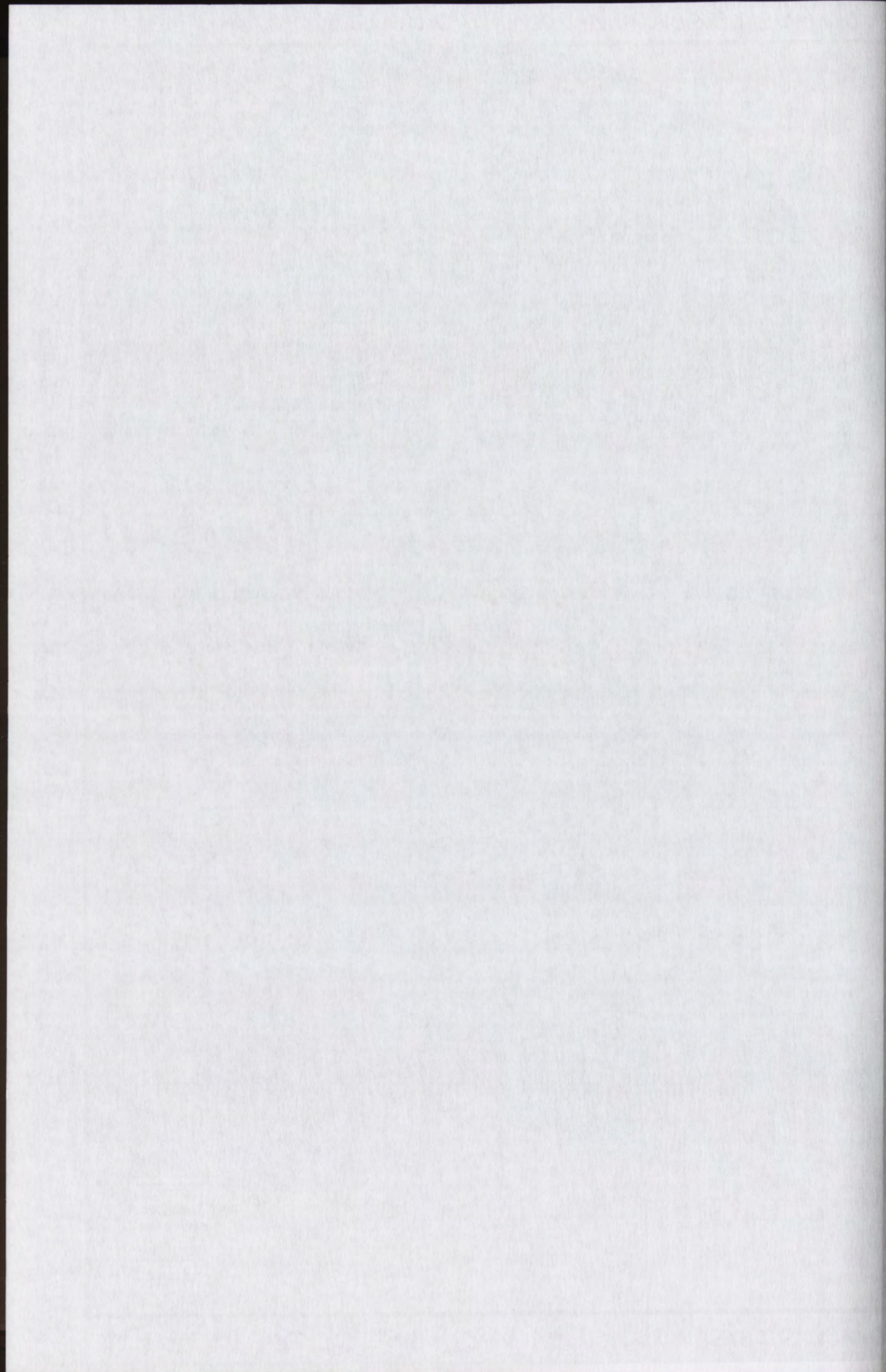
You are invited to come along and take part in a study, which will be exploring aspects of women's health, religion and culture. If you would like to make a difference to the women in your community and their health or you would like further information please contact Chandbi on: 07766147165.

Researcher: Chandbi Sange (Staff Nurse).



East Lancashire Hospitals
NHS Trust





عورتوں کی نجی صحت عورتوں کی نجی صحت عورتوں کی نجی صحت

صحت کی سلامتی ایک حق ہے گناہ نہیں

کیا زندگی کی خصوصیت پیشاب ضبط نہ ہونے سے بگڑ سکتی ہے
کیونکہ صرف اسلئے کہ آپ ایک عورت ہیں۔ تمام زندگی آپ کا
جسم بہت ساری تبدیلیوں سے گزرتا ہے۔ آپ کی جذباتی عافیت اتنی
ہی اہم ہے جتنی آپ کی جسمانی صحت۔

تقریب

آپ کو دعوت دی جاتی ہے کہ آپ انہیں اور اس مطالعے میں حصہ لیں۔ اگر آپ کو اس کے بارے
میں اور جاننا ہے ہم ایک معلوماتی اجلاس منعقد کرنے والے ہیں۔ جو کہ
(222 Audley Range (Blackburn) میں (بتاریخ) (بوقت) ہوگا۔

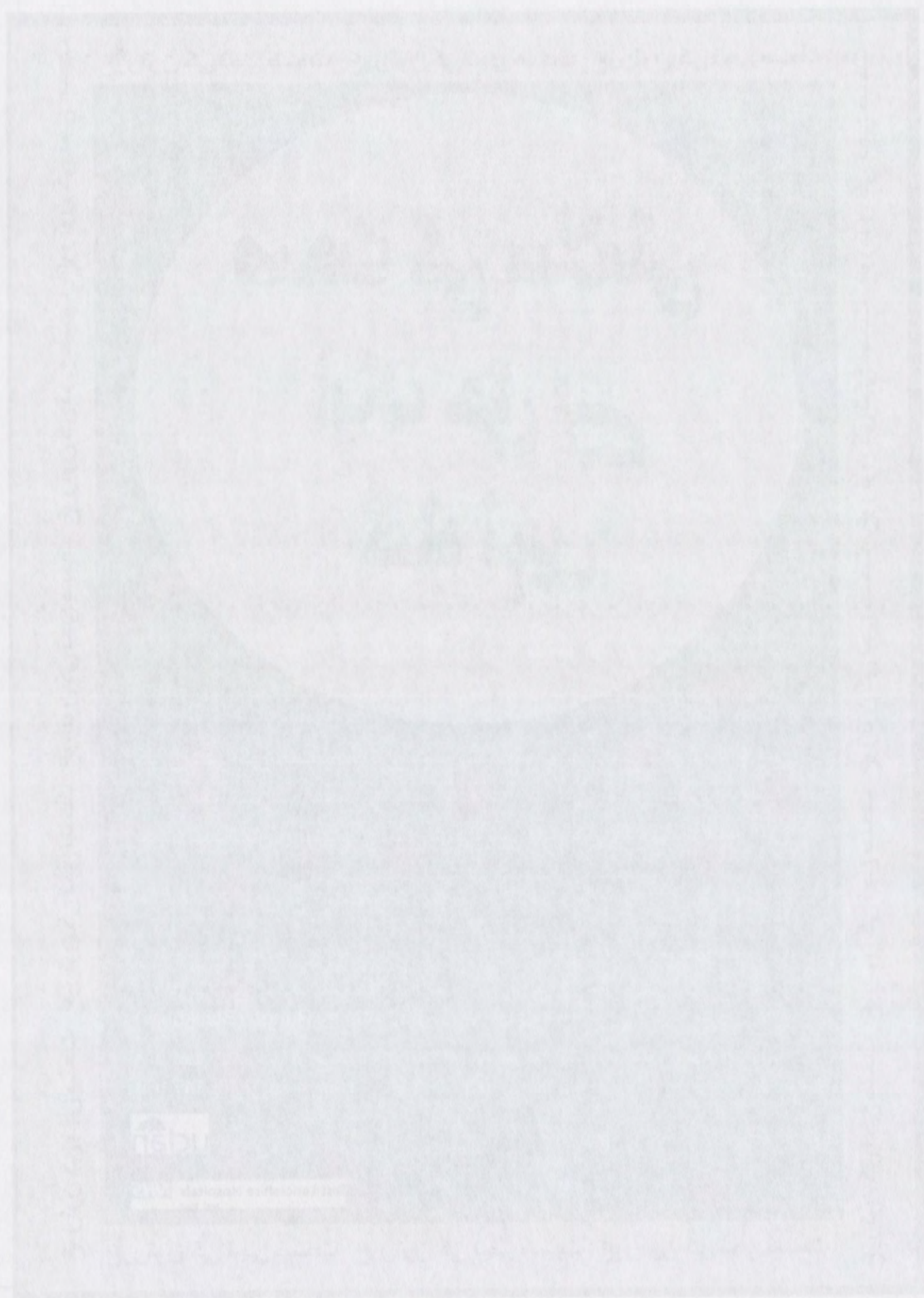
زیادہ تفصیلات حاصل کرنے کیلئے آپ تفتیشکار چاند بی سنگی سے اس ٹیلیفون نمبر پر
07766147165 رابطہ کریں۔

uclan

East Lancashire Hospitals NHS Trust

عورتوں کی نجی صحت عورتوں کی نجی صحت عورتوں کی نجی صحت

عورتوں کی نجی صحت عورتوں کی نجی صحت عورتوں کی نجی صحت



Appendix Eight:

Interview Guide for the study

Appendix Eight: Interview Guide for the study

Appendix eight: Interview Guide

Main topics to cover:

1. **urinary incontinence**
2. **culture**
3. **religion**
4. **help-seeking**
5. **decision-making**

Introduction

- Background to study
- Their background
- Where were their families from (and how does that influence their behaviour)
- Can you tell me a little bit about your health (your families)
- Describing themselves (British/Muslim)

Establish they have a problem with UI

- The duration of the problem
- Causes
- Feelings
- What do they think about it?
- How do they manage their problem?
- When did they realise they had a problem?

Can you tell me what being a Muslim means to you?

- Can you tell me the role religion plays in your daily life?
- What role does your religion play in seeking health care?
- Can you tell me of some instances where you have gone against?
- Social pressures to conform??

End:

What are your thoughts now after talking to me about (UI; your religion, and your culture?)

Prompting questions

- How did you feel about that?
- Would you do anything differently?
- Would you tell me more?
- Out of 1 to 10 how much does this affect you?

Prompt cards

Quality of life cards

You need to ask participants how their incontinence affects each of the statements

Religion and culture cards

You need to ask how each topic affects is affected by their UI.
How each impacts on their decisions around seeking help.

Appendix eight: Interview Guide

Main topics to cover:

1. urinary incontinence
2. culture
3. religion
4. help-seeking
5. decision-making

Introduction

- Background to study
- Their background
- Where were their families from (and how does that influence their behaviour)
- Can you tell me a little bit about your health (your families)
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Establish they have a problem with UI

- The duration of the problem
- Causes
- Feelings
- What do they think about it?
- How do they manage their problem?
- When did they realise they had a problem?

Can you tell me what being a Muslim means to you?

- Can you tell me the role religion plays in your daily life?
- What role does your religion play in seeking health care?
- Can you tell me of some instances where you have gone against?
- Social pressures to conform?

End:

What are your thoughts now after talking to me about (UI, your religion, and your culture)?

Prompting questions

- How did you feel about that?
- Would you do anything differently?
- Would you tell me more?
- Out of 1 to 10 how much does this affect you?

Prompt cards

Quality of life cards

You need to ask participants how their incontinence affects each of the statements

Religion and culture cards

You need to ask how each topic affects is affected by their UI.
How each impacts on their decisions around seeking help.

Appendix Nine:

Themes and Sub-themes from the Data

Appendix Nine:

Themes and Sub-themes from the Data

Appendix nine: themes and sub themes from the data

Table 12 Initial themes identified

Theme One: Urinary incontinence					
1.1 Duration of UI	1.2 Causes	1.3 When UI became a problem	1.4 Strategies for dealing with UI	1.5 Services	1.6 Knowledge about UI
Theme Two: Impact of UI on daily life					
2.1 Level of disruption to daily life	2.2 Level of disruption at work	2.3 Level of disruption at home	2.4 Disruption on social life	2.5 Feelings about UI	2.5.1 Feeling of leaking whilst praying
2.1.1 Impact of UI on praying					
Theme Three: Disclosure of UI					
3.1 Discuss with partner	3.2 Discuss with female family members	3.3 Discuss with female friends	3.4 Discuss with GP	3.5 Discuss with nurse	
			3.4.1 Discuss with male GP		
			3.4.2 Discuss with female GP		
Theme Four: Influences on help-seeking behaviour and decision-making					
4.1 What prompts them to seek help	4.2 Impact of family on help-seeking	4.3 Influences of friends on help-seeking	4.4 Influence of partner/husband on help-seeking	4.5 Influences of religion on help-seeking	
4.1.1 Restrictions			4.4.1 Restrictions	4.5.1 Restrictions	
Theme Five: Culture					
5.1 What culture means to them	5.2 Impact of culture on daily life	5.3 Impact on management of UI	5.4 Impact on help-seeking		
5.1.1 Lay aspects (personal beliefs)	5.2.1 Impact of society on daily life	5.3.1 Compliance	5.4.1 General (anxiety, circumstances)		
5.1.2 Religious aspects (dress, customs)		5.3.2 Non-compliance	5.4.2 Traditional methods (Peer saab, praying etc)		
			5.4.3 Conventional treatments		
Theme Six: Religion					
6.1 'Quran' what is actual said	6.2 People's interpretation	6.3 How they describe religion	6.4 How religion impacts on daily life	6.5 Their role as Muslim women	
6.1.1 Hadith (prophets teachings)	6.2.1 Scholars of Islam	6.3.1 What religion means to them	6.4.1 Benefits of practices	6.5.1 Men's role as perceived by	

	6.2.2 Customs and practices	'identity' 6.3.2 How others perceive their religion	(reputation) 6.4.2 Restrictions of religion (privacy, confidentiality)	women	

Theme Seven: Communication and Language

7.1 Ability to speak English	7.2 The use of Translators	7.3 Compliance to treatment	7.4 Communication with professionals
7.1.1 Unable to communicate in English	7.2.1 Translated documents		7.4.1 GP
	7.2.2 Use of family members		7.4.2 Nurses
	7.2.3 Other means of communication		7.4.3 Hospital services

Theme Eight: Media

8.1 Influences of media on health	8.2 Influences of media on religion	8.3 Influences of media on culture
8.1.1 Influences of media on UI	8.2.1 Benefits	8.3.1 Dress
	8.2.2 Barriers	8.3.2 Male domination
	8.2.3 Views of society	

Theme Nine: Family

9.1 Importance of family	9.2 Views of elders	9.3 Extended family (impact of)	9.4 Employment opportunities	9.5 Their role as women in the family
9.1.1 Over self	9.2.1 Views of partner	9.3.1 Benefits	9.4.1 Educational opportunities	9.5.1 Partner's role in family
		9.3.2 Restrictions		

Theme Ten: Cultural differences

10.1 Their upbringing	10.2 Influences on the lives of their children	10.3 Country of birth	10.4 Have you experienced racism
10.1.1 Upbringing in 'home country'	10.2.1 Practices	10.3.1 Arrival in the UK	10.4.1 Towards your dress
10.1.2 Differences in upbringing	10.2.2 Parents	10.3.2 Differences in country	10.4.2 Communication
		10.3.3 Health care in own country	10.4.3 Your beliefs and practices

Theme Eleven: Health Practices

11.1 Traditional practices	11.2 Medical conventional practices	11.3 Beliefs about ill health	11.4 Exercising	11.5 What health means to you
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Theme Twelve: Services Accessed

12.1 First port of call	12.2 Nurse specialist	12.3 Physiotherapist	12.4 Specialists
12.1.1 Communication	12.2.1 Management	12.3.1 Management	12.4.1 Management
12.1.2 Advice	12.2.2 satisfaction	12.3.2 Satisfaction	12.4.2 Satisfaction
	12.2.3 Restrictions	12.3.3 Restrictions	12.4.3 Restrictions

Appendix Ten:
Detailed table of Analysis

Appendix I

Detailed table of analysis

Table 13 selected participant's detailed quotes

	1.1 Duration of UI	1.2 Causes	1.3 When UI became a problem	1.4 Strategies for dealing for UI	1.5 Services	1.6 Knowledge about UI
	2.1 Level of disruption to daily life	2.2 Level of disruption at work	2.3 Level of disruption at home	2.4 Disruption on social life	2.5 Feelings about UI	
Aisha 28 years old. Two children. England.	Long time more drops (pg 14) Thought it would go away (pg 14)	Child birth (pg 14) Old age (pg 14)	Use to leak drops in school, but I thought it would just go away (pg 14)	I hide it (pg 14) Regular toileting (pg 14) Tena pads (pg 14) Cranberry juice (pg 14)	Doctors don't know of any (pg 16)	I thought it would just go away (pg 14)
					1.5.1 Knowledge of UI Don't know anything about UI (pg 15) People need to be made more aware of UI (pg 21) People don't know why this happens we need information (pg 21)	
Arifa 37 years old. Three children. India.	It controls me (pg 49) Not being in control I don't like (pg 49) I always wear pads (pg 49) I wont stop me (pg 49) Normal as brushing your teeth now,	I am not in my own environment so it makes it ten times worse (pg 49)	I am in my own environment so I can deal with it (pg 49)	Wear tena pads (pg 49)	Embarrassed (pg 49) It controls me (pg 49)	

	wearing a pad (pg 50)						
<p>Farzana 31 years old. Three children. Pakistan.</p>	2.1.1 Impact of UI on praying						2.5.1 Feeling of leaking urine when praying
	Yes I have leaked whilst praying (pg 55)						It makes me feel upset that I have rushed prayers and leaked when I have prayed (pg 56)
	Felt a strong desire to pass water whilst praying (pg 56)						
	I have rushed prayers to prevent a leak (pg 56)						
	3.1 Discuss with Partner	3.2 Discuss with female family members	3.3 Discuss with female friends	3.4 Discuss with GP	3.5 Discuss with nurse		
	Would not tell my husband (pg 68)	Would not tell anyone (pg 68)	My friend has the same problem so I told here, maybe she can help me (pg 69)	He is always busy but very nice doctor (pg 70)	She is very nice. I don't speak English too good but she always tries to understand me (pg 70)		
	I would not want him to know (pg 69)			I will not go to the doctors because it is a embarrassing problem and dirty thing to have (pg 77)	I have told nurse but she said it is normal at my age (pg 70)		
	Not right for a woman to tell a man about these things (pg 70)						
				3.4.1 Discuss with male GP			
				No because he is man and it is not right for a women to tell a man these things (pg 70)			
				3.4.2 Discuss with female GP			
				I would prefer a woman but sometimes there is no one (pg 73)			
	4.1 What prompts them to seek help	4.2 Impact of family on help-seeking	4.3 Influences of friends on help-seeking	4.4 Influence of partner/husband on help-seeking	4.5 Impact of religion on help-seeking behaviour		
	I think the more people become aware of UI the more likely they are to seek help	I would discuss thing with my family (pg 27)	No not really (pg 4)	For general health I would tell him but not this (pg 24)	If my health stops me from praying I would go to the		

Hajira 21 years old. Three children. England. Admin Assistant.	(pg 27)	Would consider mothers beliefs prior to medical attention (pg 27)			It's a woman's problem not to discuss with men (pg 4)	doctors (pg 26)
	5.1 What culture means to them	5.2 Impact of culture on daily life Very private everything happens at home no one should know (pg 47)	5.3 Impact of management of UI Keep clean all the time its dirty (pg 39)	5.4 Impact on help-seeking		
Rashida. 34 years old. Two. India.	5.1.1 Lay aspects (personal beliefs)	5.2.1 Impact of society on daily life Asian families all talk about each other (pg 42) We keep ourselves to ourselves don't interfere in anyone else's business (pg 42) Religion connects people together, here we are all Muslims that is why we all live tighter (pg 44)	5.3.1 Compliance Knowledge (pg 41)	5.4.1 General (anxiety circumstances) Fear of examination by a male (pg 41) Husband would not be happy (pg 40)		
	5.1.2 Religious aspects (dress, customs)		5.3.2 Non-compliance	5.4.2 Traditional methods (Peer saab praying etc)		
	These beliefs are very important to the elders of each family (pg 43)		Fear of examination by male (pg 41)	Praying is the best cure (pg 42)		
				5.4.3 Conventional treatments		
				Depends who the doctor is male or female (pg 41)		

Nadia 37 years old. Three children. England.	6.1 'Quran' what is actual said	6.2 People's interpretation	6.3 How they describe religion	6.4 How religion impacts on daily life	6.5 Their role as Muslim women
	I live my life to what is written in the Quran, praying (pg 62)	What my parents have taught me is important after religion (pg 64)	Religion is Islam the only way of life (pg 63)	Religion affects me a lot 9pg 62)	Equal to a man (pg 66)
	Women should not expose themselves to men even a doctor (pg 64)			Islam is the most important for any Muslim (pg 62)	
	6.1.1 Hadith (prophets teachings)	6.2.1 Scholars of Islam	6.3.1 What religion means to them 'identity'	6.4.1 Benefits of practices (reputation)	6.5.1 Men's role as perceived by women
	I live my life in relation to what the prophet has said (pg 62)	Religious teaching were very strict (pg 66)	I am proud of being a Muslim (pg 64)	Belonging support (pg 61)	Equal to women (pg 66)
	Women should not expose themselves to men even a doctor (pg 64)	Molvis would hit you and things if you didn't understand (pg 66)	I am a Muslim outside the home and inside the home (pg 65)		
		6.2.2 Customs and practices	6.3.2 How others perceive their religion	6.4.2 Restrictions of religion (taking men with you to doctors, privacy, confidentiality)	
		Have not read myself, informed by parents and husband (pg 62)	Wrong (pg 65)		
		Women should not expose themselves to men even a doctor. It is actually written in the Quran and Hadith (pg 64)			
		Not read self (pg 64)			
	8.1 Influence of media on health	8.2 Influence of media on religion	8.3 Influence of media on culture		
		Negative we are not all the same (pg 109)			

Salma 26 years old. Two children. England.	8.1.1 Influence of media on UI People don't talk about it (pg 107) Taboo subject (pg 107)	8.2.1 Benefits Our dress is our modesty and religion (pg 105)	8.3.1 Dress People look at you funny, but they are uncovered not use (pg 105)		
		8.2.2 Barriers	8.3.2 Male domination		
		8.2.3 Views of society People see that Muslim women have no life that is not true (pg 106) We are not terrorists (pg 109)	8.3.3		
	9.1 Importance of family Very important everyone should stay together (pg 36) Family are very important to me (pg 42)	9.2 Views of elders These practices are very important and I would expect my children to carry them and their children (pg 43) Their beliefs are very important to the elders of each family (pg 43)	9.3 Extended family (impact of) Support (pg 36) Being the eldest I had to look after everyone (pg 43)	9.4 Employment opportunities I have never worked (pg 38)	9.5 Their role as women in the family Look after home and children (pg 36)
	9.1.1 Over self I am very tried but I still need to be there for the family as much as I can (pg 36)	9.2.1 Views of partner Very important (pg 43)	9.3.1 Benefits Support (pg 43)	9.4.1 Educational opportunities Parents did not allow us to go to school (pg 43) I was the eldest so I had to look after the family (pg 43)	9.5.1 Partner's role in family To earn and provide (pg 36)
Khalsoom. 26 years old. Two children. India.			9.3.2 Restriction I only went out the house to wash clothes (pg 43)		

<p><i>Nosheen. 42 years old. Four children. Pakistan.</i></p>	9.1 Importance of family	9.2 Views of elders	9.3 Extended family (impact of)	9.4 Employment opportunities	9.5 Their role as women in the family
	My family are very important to me (pg 117)	I encourage my parents practices with my children to a certain extent (pg 112)	My family live near by, its nice at family gatherings and things when everyone gets together (pg 117)	Store manager (pg 112)	Same as a man to a certain extent (pg 112)
	9.1.1 Over self	9.2.1 Views of partner	9.3.1 Benefits	9.4.1 Educational opportunities	9.5.1 Partner's role in family
	I have to be healthy to look after them (pg 117)	We work together to make our lives better (pg 117)	As above (pg 117)		Same as mine (pg 112)
	10.1 Their upbringing	10.2 Influences on their life as children	10.3 County of Birth	10.4 Have you experienced racism	
<p><i>Noreen. 26 years old. One. England.</i></p>	Very strict (pg 29)	Things will change. I would not stop them going to college and things like that (pg 29)	UK (pg 29)	People don't see you they see your skin colour first (pg 29)	
	10.1.1 Upbringing in 'home country'	10.2.1 Practices	10.3.1 Arrival to UK	10.4.1 Towards your dress	
	Girls should stay home, my parents are bought up that way I suppose (pg 29)	My husbands believes still have not changed, the girls should stay home, but I hope one day they will (pg 30)			
	Parents from Pakistan and so is husband (pg 29)				
	10.1.2 Differences in upbringing	10.2.2 Parents	10.3.2 Differences in country	10.4.2 Communication	
	Its not normal in Pakistan for a girl to work so that is why I don't (pg 30)	Parents from Pakistan (pg 29)	Pakistan is nice. All our people are there. Nice no fighting like here (pg 29)		
		Refused to let go college (pg 29)			
		10.2.3 Husband and his family		10.4.5 Your beliefs and practices	
		My husband has totally			

		influenced my and his family, I asked them if I could work and they refused (pg 30)				
Sobia. 58 years old. Six children. Pakistan.	10.1 Their upbringing			10.3 Country of birth	10.4 Have you experienced racism	
	Very strict my parents did not let us do things outside the house (pg 121)			India (pg 119)	Everyone use to get along before, you are scared to leave your house (pg 119)	
	10.1.1 Upbringing in 'home country'			10.3.1 Arrival in the UK 1960's (pg 119)	10.4.1 Towards your dress	
				I was really excited when I came into this country (pg 120)		
	10.1.2 Differences in upbringing			10.3.2 Differences in country	10.4.2 Communication	
	More freedom here (pg 121)			The weather (pg 120)	It must be a pain, but if I don't understand then what do I do (pg 122)	
Fatima. 70 years old. Seven children. India.				I had never seen snow before (pg 120)		
				10.3.3 Health care in own country	10.4.3 Your beliefs and practices	
				We don't have to pay here but if you have money in India then you are ok but if you don't then it is hard (pg 121)		
	11.1 Traditional practices			11.3 Beliefs about ill health	11.4 Exercise	11.5 what health means to them
	The best way to make you feel better is by praying to Allah (pg 5)			Good and bad are from Allah and we should accept it (pg 7)	Go for walks with friends	To not have any illness or take medication (pg 5)
	I ask Peer Saab for advice too (pg 6)			Illness purifies our souls (pg 7)		
	11.1 Traditional practices			11.3 Beliefs about ill health	11.4 Exercise	

<p><i>Fozia. 26 years old. Two children. England.</i></p>	Praying (pg 14)	If I need help I will go to the doctors (pg 14)	If ill health is stopping you from performing prayers and looking after family then you have the ability to go and do something about it (pg 14)	Don't get time to exercise (pg 13)	
				11.4.1 Restrictions	
				Gyms don't cater for Muslim women (pg 13)	
<p><i>Shenaz. 67 years old. Seven children. Pakistan.</i></p>	11.1 Traditional practices	Our Peer helps us a lot and guides us (pg 84)	11.2 Medical conventional practices	Mixed Gyms (pg 13)	11.5 What health means to you
		We pray to Allah for better health (pg 86)	I take medicines (pg 82)	11.4 Exercising	
			No point worrying about illnesses (pg 79)	We don't exercise I walk sometimes just around here if I can (pg 84)	I am always tired and ill now (pg 79)
<p><i>Farhat. 46 years old. Five children. Pakistan.</i></p>	1.1 Duration of UI	1.2 Causes	1.3 When UI became a problem	1.4 Strategies for dealing for UI	1.5 Services
	8 years now' (pg 3)	Having children I think' (pg 3)	The problem became bad and worse I had to go to the doctors' (pg 5)	'I get pads ... from the NHS' (pg 3)	Nurses, exercise lady, doctor (pg 3)
		My children were big babies (pg 3)		I still wear pads' (pg 5)	
<p><i>Shagufa. 54 years old. Seven children. Pakistan.</i></p>	2.1 Level of disruption to daily life	2.2 Level of disruption at work	2.3 Level of disruption at home	2.4 Disruption on social life	2.5 Feelings about UI
	I have to always wear pads now cause I don't know when it is going to come out (pg 17)	I don't work (pg 17)	My husband helps me with housework now because of this, he does the Hoover (pg 17)	If I go out I wear pads but I don't go out much (pg 18)	'Its embarrassing telling someone you have this problem' (pg 16)
					it gets me down' (pg 18)

	<i>2.1.1 Impact of UI on praying</i>						<i>2.5.1 Feeling of leaking when praying</i> it gets me down' (pg 18)
	I have leaked urine loads of time when praying namaz' (pg 18)						
	<i>3.1 Discuss with Partner</i>					<i>3.4 Discuss with GP</i>	<i>3.5 Discuss with nurse</i>
<i>Shahista. 54 years old. Three children. Pakistan.</i>	I told my husband... I tell him everything' (pg 17)			<i>3.2 Discuss with female family members</i> My daughter knows (pg 19)	<i>3.3 Discuss with female friends</i> I don't tell anyone outside the family about any problems (pg 19)	I can see a male or female. They speak our language' (pg 18)	Only told you because you are a nurse (pg 16)
						<i>3.4.1 Discuss with male GP</i> I would see a male doctor... its embarrassing but' (pg 19)	
						<i>3.4.2 Discuss with female GP</i> I can see a male or female doctor... I told the lady doctor... this was a woman's problem so it was easier telling her' (pg 18)	
<i>Khalida. 42 years old. Four children. India.</i>	<i>4.1 What prompts them to seek help</i>			<i>4.2 Impact of family on help-seeking</i>	<i>4.3 Influences of friends on help-seeking</i>	<i>4.4 Influence of partner/husband on help-seeking</i>	<i>4.5 Influences of religion on help-seeking</i>
	Ill health, when a problem is worse when I am unable to cope (pg 22)			My daughter comes with me' (pg 22) My daughter pushed me to go to the doctors (pg 23)	My daughters and family are my friends (pg 24)	He is not alive, when he was we used to discuss everything (pg 24)	You should go to the doctors if you have a problem even if they are men. If you have a illness and doctors can help' (pg 24)
	<i>4.1.1 Restrictions</i> Bad experiences (pg 25)					<i>4.4.1 Restrictions</i> He is no more (pg 24)	<i>4.5.1 Restrictions</i> There is no restrictions in my religion (pg 24)
	<i>5.1 What culture means to them</i>			<i>5.2 Impact of culture on daily life</i> We are all same and we can relate to each other (pg 41)	<i>5.3 Impact of management of UI</i> I wanted a operation first but I have to try exercises (pg 40)	<i>5.4 Impact on help-seeking</i>	
	This area people around us (pg 41)					I should go to the doctors if this makes me better' (pg 39)	

<p><i>Ghazala. 76 years old. Two children. Pakistan.</i></p>	5.1.1 Lay aspects (personal beliefs)	5.2.1 Impact of society on daily life	5.3.1 Compliance	5.4.1 General (anxiety circumstances)	
	‘Would not go to male for female problems, it doesn’t look right’ (pg 37)	Asian families around here, it is nice people are just like you, people speak your language it is like a big family (pg 41)	I just agree with what they say, I just want them to make me better (pg 40)	they cant do anything for me’ (pg 38)	
	I have been bought up and told girls should not work and they shouldn’t (pg 35)				
	Every woman should have a son, it must be hard for your parents (pg 35)				
	5.1.2 Religious aspects (dress, customs)		5.3.2 Non-compliance	5.4.2 Traditional methods (Peer praying etc)	
<p><i>Ghazala. 76 years old. Two children. Pakistan.</i></p>	Girls should not work (pg 35)		‘Would not go to male for female problems, it doesn’t look right’ (pg 37)	I even asked peer Saab, he said the same thing, I have a infection’ (pg 37)	
	Men should work and provide for us (pg 35)		they cant do anything for me’ (pg 38)	‘[peer Saab] I should pray and things’ (pg 37)	
				5.4.3 Conventional treatments	
				‘Doctors have medicine for everything’ (pg 37)	
	6.1 ‘Quran’ what is actual said	6.2 People’s interpretation	6.3 How they describe religion	6.4 How religion impacts on daily life	6.5 Their role as Muslim women
	Girls should not work (pg 35)	But if your parents don’t have sons then you lot have to work (pg 35)	My religion is Pure because we come from Pakistan. (pg 38)	Religion is very important (39)	To stay in the house and look after children (pg 34)
	Muslim girls should not work. It is not right them mixing in with other men (pg 35)			Feel like I cant pray or anything because of this problem (pg 39)	
	Islam says I should go to the doctors if its going to make me feel better and allow me to pray (pg 39)				

	6.1.1 Hadith (prophets teachings)	6.2.1 Scholars of Islam	6.3.1 What religion means to them 'identity'	6.4.1 Benefits of practices (reputation)	6.5.1 Men's role as perceived by women
	Girls should not work (pg 35) Muslim girls should not work. It is not right them mixing in with other men (pg 35)	Muslim girls should not work. It is not right them mixing in with other men (pg 35)	I am a Muslim (pg 39)	You become closer to Allah (pg 40)	To look after his family and provide for them (pg 34)
		6.2.2 Customs and practices	6.3.2 How others perceive their religion	6.4.2 Restrictions of religion (taking men with you to doctors, privacy, confidentiality)	
		I even asked peer Saab, he said the same thing, I have a infection' (pg 37) Girls should not work (pg 35) I have been bought up and told girls should not work and they shouldn't (pg 35) Muslim girls should wear Asian clothes but here you lot don't that is wrong god will punish you lot (pg 35)	Who cares what others think we know our religion (pg 41)	Girls should not work (pg 35)	
Tayiba. 63 years old. Seven children. Pakistan.	7.1 Ability to speak English	7.2 The use of Translators	7.3 Compliance to treatment	7.4 Communication with health professionals	
		N/A	Communication and knowledge (pg 47)	I cant speak English at all (pg 46)	
	7.1.1 Unable to communicate in English	7.2.1 Translated documents		7.4.1 GP	
	I cant speak English at all (pg 46)	I have seen them but I cant read it, because words I don't understand (pg 46)		'[GP] Female... yes she speaks Urdu and English (pg 49)	take my daughter in law with me because sometimes I don't

						understand what they say' (pg 46)	
						7.4.2 Nurses	
						My nurse at the surgery is English too, I take someone with me. She is very nice (pg 46)	
						7.4.3 Hospital services	
						I take my daughter in laws with me I cant speak English and most of them are English (pg 46)	
						8.3 Influence of media on culture	
						People see Muslim women as soft and stuck in the house that is not true (pg 54)	
						8.3.1 Dress	
						This is my dress. Muslim women and girls should cover up (pg 51)	
						Here we have to change as long as you are not showing your body I don't think you are doing anything wrong (pg 52)	
						8.3.2 Male domination	
						Yes men can do what they want (pg 51)	

		I can understand people can be funny towards you (pg 54)				
		8.2.3 Views of society				
		We are not all the same (pg 540)				
	9.1 Importance of family	9.2 Views of elders	9.3 Extended family (impact of)	9.4 Employment opportunities	9.5 Their role as women in the family	
	My children and only my children are everything to me (pg 52)	My parents did not support me when my husband left (pg 51)	I don't bother with them no more (pg 58)	I have told my girls to work and they should we didn't get chance (pg 50)	To take of my children (pg 53)	
	9.1.1 Over self	9.2.1 Views of partner	9.3.1 Benefits	9.4.1 Educational opportunities	9.5.1 Partner's role in family	
	No because health comes first, if I am well I can do things (pg 52)	I use to listen to everything what he told me and believed it I made a big mistake (pg 51)	'I take my daughter with me when I go to doctors (pg 54)	I didn't have the chance but my eldest daughter is a teacher, the other is doing law (pg 49)	My husband left me for a white woman (pg 50)	
			9.3.2 Restriction			
			My daughter knows I have this problem now (pg 54)			
	10.1 Their upbringing	10.2 Influences on their life as children	10.3 Country of birth	10.4 Have you experienced racism		
	My parents very strict (pg 62)	My children don't like it in Pakistan (pg 62) You lot that have been born here think you are like them (pg 62)	Pakistan (pg 61)			
	10.1.1 Upbringing in 'home country'	10.2.1 Practices	10.3.1 Arrival in the UK	10.4.1 Towards your dress		
	My parents are still very strict. I never sat in front of my father or even in the same room. (pg 62)	There is no point for a girl to be educated because they are someone else property (pg 62)	30-40 years			

Nazia. 54 years old.
Four children.
Pakistan.

Nusrat 54 years old.
Three children.
Pakistan.
Housewife.

	10.1.2 Differences in upbringing You should never forget your roots (pg 62)	10.2.2 Parents My parents did not let us go to school, because they could not afford it (pg 62)	10.3.2 Differences in country By the time they [professional] do anything I will be dead. I wish I had gone to Pakistan and got operation done there' (pg 66) Very nice country our people are there (pg 62) You lot don't care here (pg 62)	10.4.2 Communication They think this lady cannot speak English we don't care what they say and just agree' (pg 65)	
			10.3.3 Health care in own country 'I would pay for services in Pakistan, and be seen straight away, I would get a woman doctor too' (pg 66) I will go and get treatment done in Pakistan' (pg 66)	10.4.3 Your beliefs and practices	
	11.1 Traditional practices The best form of treatment is praying and following the path of our prophet (pg 68)	11.2 Medical conventional practices I am waiting for a operation now (pg 69)	11.3 Beliefs about ill health 'I have full faith in my God' (pg 70) God has given me the knowledge to do something about it' (pg 70)	11.4 Exercising Exercising are you joking that is impossible with three young kids (pg 69)	11.5 What health means to you I have had a lot of problems, but I never lost faith, Thank God things may be getting better for me' (pg 70)
Roshin. 28 years old. Three children. England.	12.1 First port of call Told my GP (pg 74)	12.2 Nurse specialist I see Mary and the nurse, they give me tablets' (pg 75)	12.3 Physiotherapist Mary told me because you have children, but I no children' (pg 75)	12.4 Specialists 'I asked for a female doctor but there was not one available' (pg 77)	
	12.1.1 Communication They speak Urdu (pg 74)	12.2.1 Management Tablets (pg 75)	12.3.1 Management Exercises (pg 75)	12.4.1 Management	
Hameeda. 46 years old. Africa. None.					

	12.1.2 advice	12.2.2 Satisfaction	12.3.2 Satisfaction	12.4.2 Satisfaction	
	They don't care about me because I have had loads of problems, so they just sent me to hospital (pg 74)	'I never took the tablets [non compliance]' (pg 74)			
		12.2.3 Restriction	12.3.3 Restriction	12.4.3 Restriction	
		'[tablets] don't work, it is still the same, they did tell me if this doesn't work than I will get a operation' (pg 75)			

Appendix Eleven:
Matrix Table of Analysis

Appendix Eleven: Matrix Table of Analysis

Appendix eleven: Matrix table

Table 14 final stages of analysis

Identified themes and sub themes from women who have sought help.

Theme One: Urinary Incontinence						
	Sub theme: 1.1 Duration	Sub theme: 1.2 Causes	Sub theme: 1.3 When UI became a problem	Sub theme: 1.4 Strategies for dealing with UI	Sub theme: 1.5 Services	Sub theme: 1.6 Knowledge
Summary	Time line varied considerable.	Generally, participants stated vaginal childbirth has caused UI.	All participants stated their UI had become severe that was when they decided to seek help.	Strategies for dealing with UI mainly consisted of wearing pads most of the time.	All participants were aware of who they had to see and in what order.	Participants felt their knowledge about UI had increased.
No of participants	Less than 1 year: 1 participants stated had been suffering for 5 months. Less than five years: 3 participants stated less than 5 years. More than 5 years: 4 participants stated they have suffered for over 5 years. Long time: 7 participants stated they had suffered form UI for a very long time.	Childbirth: 11 participants stated vaginal childbirth causes UI. Old age: 1 participant stated it was a normal part of ageing. Other illnesses: 2 participants stated other illnesses cause UI. Infections: 2 participants stated UI is caused by UTI's. Don't know: 1 participant stated she had no idea why people get UI.	Severity: 14 participants stated severity was one reason they sought help.	Pads: 14 participants wore pads on a daily basis. Restricting fluids: 3 participants restricted fluid intake. Self catheterise: 1 participant was shown how to self catheterise. Exercises: 2 participants completed pelvic floor exercises on a regular basis. Medication: 1 participant took medication. Diary: 1 participant mentioned the bladder diary.	Physio: 12 participants had seen the physiotherapist. Nurse: 9 participants had seen the nurse specialist. Consultant: 7 participants had seen the consultant.	Knowledge: 4 participants stated their knowledge about UI had increased dramatically. Taboo: 4 participants stated people don't want to talk about UI. Don't know: 3 participants did not feel they knew anything about UI. No time: 2 participants had any time to read the information that had been provided, and preferred people telling them about it. Normal: 1 participant stated it was a normal part of ageing. Not given info: 1 participant stated she was not given information about UI.
Illustrative quotes	'Very long time, about	'Having children I	'The problem became	'I get pads ... from the	'The physio shows	'I know more about

nine years now' (pg 44) Nusrat	think... 'My children were big babies (pg 3) Farhat 'Being old' (pg 38) Ghazala 'I had infection in womb... since then I had this problem... that was in 1985 (22years)' (pg 55) Nusrat 'I think because I take three water tablets, that is why I leak' (pg 75) Hameeda	bad and worse I had to go to the doctors' (pg 5) 'When it got worse, that is when I thought I had to do something about it' (pg 27) Khalida 'When it started happening more and more than I thought this is not normal, I need to do something about this' (pg 87) Sofia	NHS' (pg 3) Farhat 'I don't even drink water ... just in case I leak' (pg 24) Shahista	exercises, the nurse gave me tablets, and the doctor for operation (pg 18) Shagufta 'I want a operation that is only going to make me better now (pg 65) Nazia	incontinence now than I ever did' (pg 5) Farhat 'I don't know much about this. I did get information from physio but I have not had time to read it (pg 11) Naila 'No one tells you about this, if we knew I think we wouldn't let it get this bad... 'UI is a illness... its not normal, you only get medication for illnesses' (pg 20) Shagufta 'I thought it was normal when it started (pg 22) Shahista 'We didn't get much information about it' (pg 46) Tayiba
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Theme Two: Impact of UI on daily life

Sub theme: 2.1 Level of disruption to daily life		Sub sub theme: 2.1.1 Impact of UI on praying	
Summary	Major theme to emerge was that all participants wore pads on a daily basis; some felt it had become a habit now.	All (14) participants stated they either leaked or rushed prayers due to UI.	
No of participants	Don't let it stop me: 3 participants stated they would not let leaking urine a major issue in their lives. Pads: all (14) participants wore pads. Always think about it: 3 participants would always think about leaking urine. Regular toileting: 2 participants would toilet themselves on a regular basis to prevent leakage. Leak all the time: 2 participants had no control what so ever over their bladder.	Rushed: 3 participants would rush prayers to prevent leakage. Leaked: 7 participants stated they had leaked urine whilst praying. Cannot pray: 4 participants had been unable to pray due to leaking urine all the time. N/A: 1 participant felt leaking urine was not so bad that it interfered with her praying.	

	<p>Habit: 2 participants felt UI had become a part of their life, but did not over take their lives.</p> <p>'I don't let it stop me... but it does upset me... 'You just learn to accept it (pg 4) Farhat</p> <p>'Leaking urine does make my life bad but not unbearable... I don't have any major illnesses' (pg 12) Naila</p> <p>'I cannot do anything without thinking I am going to leak... 'I have to go to the toilets every couple of hours' (pg 24) Shahista</p>		<p>"I have had to rush so many times when praying' (pg 14) Naila</p> <p>"I decided to go doctors because this came between me and praying' (pg 28) Khalida</p> <p>"I haven't even prayed namaz for two years because of this' (pg 37) Ghazala</p> <p>'I have done wadu at least 4-5 times in one namaz (pg 56) Nusrat</p> <p>'Leaking urine ... came between me and praying (pg 70) Roshin</p> <p>"Since this has happened [UI] I have not prayed namaz for two years, I have not prayed Quran at all' (pg 76) Hameeda</p>
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Theme Two: Impact of UI on daily life

<i>Summary</i>	<i>Sub theme: 2.2 Level of disruption at work</i>	<i>Sub theme: 2.3 Level of disruption at home</i>	<i>Sub theme: 2.4 Disruption on social life</i>
<p>Participants did not work outside the house.</p> <p>Don' work: 13 participants did not work outside the house.</p> <p>Girls should not work: 5 participants felt girls should not be working.</p> <p>Work: 10 participants did work, but had to leave due to their UI. 1 participants continued employment, as long as she wore pads, she was fine.</p>	<p>Participants did not work outside the house.</p> <p>Don' work: 13 participants did not work outside the house.</p> <p>Girls should not work: 5 participants felt girls should not be working.</p> <p>Work: 10 participants did work, but had to leave due to their UI. 1 participants continued employment, as long as she wore pads, she was fine.</p>	<p>Mix responses. Some participants stated them leaking urine stopped them from doing house hold tasks; some stated they would not let it get in the way.</p> <p>Pads: 2 participants wore pads all the time at home too. Plastic covers: 2 participants used plastic covers on the sofa and bed to prevent wetting.</p> <p>Unable to do anything: 5 participants felt leaking urine for them was a major issue as they could not stand without leaking.</p> <p>Don't let it get in the way: 3 participants stated they did not let leaking urine get in the way of their daily tasks.</p> <p>Husband: 1 participant stated her husband helped with house work due to her UI.</p> <p>Relationship: 2 participants stated they were unable to have a sexual relationship with their partners due to UI.</p> <p>'I place a plastic cover on my bed... 'If I don't wear pads then there it is everywhere (pg 5) Farhat</p>	<p>Mainly participants did not leave their house for long periods due to UI.</p> <p>Don't go out: 13 participants stated they either did not go out the house at all. If participants left the house it was only for short periods.</p> <p>Pads: 2 participants stated UI did not restrict them from going out, as long as they wore pads.</p>
<i>Illustrative quotes</i>	<p>'I use to work in a Bakery but I had to leave because of this problem (pg 22) Shahista</p>		<p>'I don't go out much because of this problem' (pg 5) Farhat</p> <p>'I feel like I am locked in the house' (pg 14) Naila</p>

	<p>'I do go out to work, as long as I know where the toilets are I am ok and I wear pads (pg 31) Neelam</p> <p>'Leak urine every 15 to 20 minutes' so I couldn't work (pg 52) Nusrat</p>	<p>'My husband helps me with housework now because of this, he does the Hoover (pg 17) Shagufta</p> <p>'I don't let me leaking urine come between me and my family, they don't know' (pg 33) Neelam</p> <p>'I don't even have a sexual relationship with my husband' (pg 64) Nazia</p> <p>'I put a plastic cover on the sofa before I sit down... because it just comes out' (pg 75) Hameeda</p>	<p>'If I go out I wear pads but I don't go out much (pg 18) Shagufta</p> <p>'I don't go to family gatherings because of this...' My problem has become so bad I don't go out anywhere' (pg 24) Shahista</p> <p>'I don't go out much...I wear pads...or I don't stay out long'(pg 29) Khalida</p> <p>'I don't go out at all; this is my life in this house. I am safe in my house' (pg 39) Ghazala</p> <p>'I am embarrassed of going out the house' (pg 75) Hameeda</p>
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Theme Two: Impact of UI on daily life		
	Sub theme: 2.5 Feelings about UI	
Summary	Participants felt a sense of embarrassment and feeling dirty when they leaked urine.	Sub sub theme: 2.5.1 Feeling of leaking whilst praying Participants felt there was a barrier between themselves and their God due to UI. Clean and unclean theory was mentioned on numerous occasions, and cleans (not leaking) is what kept them near God.
No of participants	<p>Dirty: 10 participants felt dirty having this problem.</p> <p>Embarrassed: 6 participants felt embarrassed.</p> <p>Lonely: 2 participants stated they felt very lonely although living in a large family.</p> <p>Taboo: 3 participants stated due to the subject area being so private, things were not discussed.</p> <p>Habit: 5 participants stated leaking urine has become a part of their life.</p>	<p>Barrier: 3 participants felt there to be a barrier between them and their God due to leaking urine.</p> <p>Depressed: 6 participants felt down because they had either leaked or were unable to pray.</p> <p>Not prayed: 2 participants had not prayed for some time now.</p> <p>Clean/unclean theory: 5 participants mentioned the clean unclean theory, in relation to praying.</p> <p>Punishment: 4 participants felt they were being punished for sins they may have committed.</p> <p>Cried: 1 participant stated she had cried on a daily basis, because of her UI.</p> <p>'I have not prayed for some time now I feel like it is a punishment (pg 24) Shahista</p>
Illustrative quotes	<p>'I think do I smell, its horrible I cant explain' (pg 7) Farhat</p> <p>'Leaking urine does affect me being happy, it gets me down a lot at my age should you really have this problem' (pg 12) Naila</p> <p>'Its embarrassing telling someone you have this problem' (pg 16) Shagufta</p>	<p>'When praying all your attention should be to Allah and mine is not because of this (pg 24) Khalida</p> <p>'When we pray we need to be clean, if you leak you are unclean...'I have</p>

	<p>'I feel lonely and stuck in the house (pg 22) Shahista</p> <p>'Very embarrassed, I felt dirty and ashamed of myself' (pg 28) Khalida</p> <p>'I feel like a baby with these nappies (pg 43) Tayiba</p> <p>'Children have this problem, why am I at 46... 'I use to be so confident and independent...but now I have no confidence... 'I feel so depressed and lonely' (pg 73) Hameeda</p>	<p>not leaked but rushing prayers is not good is it (pg 31) Neelam</p> <p>'Even God is mad with me' (pg 76) Hameeda</p>
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Theme Three: Disclosure of UI				
	Sub theme: 3.1 Discuss with partner			
Summary	Sub theme: 3.2 Discuss with female family members	Sub theme: 3.3 Discuss with female friends	Sub theme: 3.4 Discuss with nurse	
General idea was that participants never discussed women issues with their partners for a number of reasons. Some women did tell their husbands about UI.	Participants preferred telling their daughters the main reason was that their daughters would accompany them to hospital appointment.	Overall theme was that problems within the house should not be taken outside the house. All those with friends were all female.	Mix responses, some participants stated they would not discuss UI with their PN because they were not doctors. Other felt they would, but lacked in the communication side of things.	
No of participants	<p>Never: 8 participants would not discuss UI with their husbands because they felt it was a women's problem and men should not know.</p> <p>Yes: 5 participants discussed their UI with their partners, and felt they were very supportive.</p> <p>Other circumstances: 2 participant's husbands had left them. 1 participant's husband had died. 1 participant would never discuss anything with her husband.</p>	<p>No, don't take outside the house: 10 participants stated UI is not a topic to be discussed with anyone outside or inside the house.</p> <p>No, don't have friends: 3 participants stated they did not have any friends; their life started with their family and will end with them.</p> <p>Yes: 1 participant stated she would discuss with her friends, as same age.</p>	<p>No, not doctor: 4 participants stated they would not discuss UI with a nurse.</p> <p>No: 1 participant would not discuss with nurse for no apparent reason.</p> <p>Communication barrier: 3 participants would have discussed with nurse but were unable to speak English.</p> <p>Yes: 3 participants felt they would be able to discuss with the nurse and health problems, and had already discussed UI.</p> <p>N/A: 2 participants did not comment.</p>	
Illustrative quotes	'It is not a thing to tell your husband...it is so embarrassing, it's a woman's problem' (pg 6) Farhat	'My daughter knows, but no one else...It is ok telling girls because it is a ladies problem (pg 6) Farhat	<p>'My friends know, but they have this problem too' (pg 7) Farhat</p> <p>'I don't tell anyone outside the</p> <p>'Might be difficult because I cant speak English (pg 130) Naila</p> <p>'No because they wouldn't know</p>	

	<p>'I told my husband... I tell him everything' (pg 17) Shagufta</p> <p>'I only told my husband (p 30) Neelam</p> <p>'I would never tell any male, no never' (pg 39) Ghazala</p> <p>'My husband knows now too because I leaked in front of him ' (pg 66) P 10</p> <p>'I don't even have a sexual relationship with my husband' (pg 64) Nazia</p> <p>'There are some things I would never discuss with my husband especially women problem. There is some sort of barrier' (pg 70) Roshin</p> <p>'I don't tell him anything he does not have time for me at all (pg 77) Hameeda</p> <p>'It's a woman thing so I felt horrible and dirty telling him' (pg 88) Sofia</p>	<p>'I told one of my sister in laws about this' (pg 14) Naila</p> <p>'I cant tell anyone else about this I wouldn't want everyone to know (pg 33) Neelam</p> <p>'My mums knows and that is enough' (pg 71) Roshin</p> <p>'I don't have anyone here at all I am so lonely (pg 77) Hameeda</p>	<p>family about any problems (pg 19) Shagufta</p> <p>'I don't want anyone to know its not something you can tell people (pg 81) Ameena</p>	<p>(pg 24) Shahista</p> <p>'I thought it was normal because the nurse told me' (pg 26) Khalida</p>
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Theme Three: Disclosure of UI	
<i>Summary</i>	<p>Sub theme: 3.5 Discuss with GP All participants stated they would discuss and had discussed UI with their GP's.</p> <p>Sub sub theme: 3.5.1 Discuss with male GP Mix response, some participants would discuss UI with male GP', some would not.</p> <p>Sub sub theme: 3.5.2 Discuss with female GP All participants preferred to tell a female GP about UI.</p>
<i>No of participants</i>	<p>Yes: all participants.</p> <p>Yes: 11 participants stated they would discuss UI with a male GP.</p> <p>No: 2 participants would not discuss women problems with a male GP.</p> <p>Communication: 8 participants that stated yes, was because their GP spoke Urdu.</p> <p>Examination: 1 participant stated she would only discuss, but refuse to be examined by any male.</p> <p>Yes: participants preferred female GP.</p>
<i>Illustrative quotes</i>	<p>'I can see a male or female. They speak our language' (pg 18) Khalida</p> <p>'I told the lady doctor because it was a lay problem (pg 86)' Sofia</p>

	<p>'You should go to the doctors if you have a problem even if they are men. If you have a illness and doctors can help' (pg 24) Shahista</p> <p>'I can talk to my GP about anything' (pg 32) Neelam</p> <p>'Doctors have medicine for everything' (pg 37) Ghazala</p> <p>'I will ask for a woman, if one is not around I will not go I will have to live with it' (pg 65) Roshin</p> <p>'My doctors don't give a shit about me or my problems' (pg 74) Hameeda</p>	<p>'If I have to go to see a man I wouldn't want any help at all' (pg 13) Naila</p> <p>'Is does bother me [GP being male], that is why I told my nurse first because she is a woman' (pg 27) Khalida</p> <p>'I suppose if I have problem and only man can see me than I have to go' (pg 37) Ghazala</p> <p>'I would talk to him but not let him examine me (pg 48) Tayiba</p>	
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Theme Four: Influences on help-seeking behaviour and decision-making

	Sub theme: 4.1 What prompts them to seek help	Sub sub theme: 4.1.1 Restrictions
Summary	Severity of illness prompted participants to seek help.	Main theme was that participants feared examination by a male doctor.
No of participants	Severity: 7 participants stated depending on how severe the problem was they would seek help. Ill health: 7 participants stated an illness would prompt them. Knowledge: 1 participant stated knowledge about an illness prompts them. Peer Saab: 1 participant stated they would consult their Peer Saab prior to seeking help.	Examination: 9 participants feared examination by a male doctor. Communication: 3 participants did not feel confident in their communication. Lack of knowledge: 2 participants stated lack of knowledge about an illness prevented them seeking help. None: 1 participant did not comment.
Illustrative quotes	'Illness, not being able to cope with the problem (pg 2) Farhat	'Communication and language, the gender of the doctor (pg 7) Naila
	'It can get worse, which I don't want that is why I decided to go to get myself sorted' (pg 82) Ameena	'Would never let a male doctor examine her...I would juts put up with whatever problem I had' (pg 47) Tayiba

Theme Four: Influences on help-seeking behaviour and decision-making

	Sub theme: 4.2 Impact of family on help-seeking	Sub theme: 4.3 Influence of friends on help-seeking
Summary	Mainly participants felt the influence of their daughter about seeking help mattered and were influenced by them.	General theme was that participants would not discuss something so personal to anyone outside the house, not even their friends.

<i>No of participants</i>	Daughter: 6 participants stated their daughter had pushed them to seek help. I decide: 4 participants would decide themselves. Wellness: 3 participants stated to a certain extent family did impact, if they were not well they would not be able to look after their families.	Don't take things outside the house: 12 participants would not discuss ill health with their friends, so they did not impact on them seeking help. Don't have friends: 2 participants stated they did not have any friends.
<i>Illustrative quotes</i>	<p>'My daughter has been very supportive all the way through this (pg 7) Farhat</p> <p>'My family does not affect me seeking help, although if I am well I can look after them' (pg 14) Naila</p> <p>'It is only me and my husband here, but I tell him everything (pg 17) Shagufta</p> <p>'Yes they do. They are only looking out for me and helping me' (pg 45) Tayiba</p> <p>'I discuss things with my mum and husband especially if its about illnesses (pg 69) Roshin</p> <p>'I do tell my mum things but I decide to go to the doctors myself (pg 82) Hameeda</p>	<p>'I don't take things out the house (pg 7) Farhat</p> <p>'Would not tell anyone outside the family home' (pg 47) Tayiba</p>

Theme Four: Influences on help-seeking behaviour and decision-making		
<i>Summary</i>	Sub theme: 4.4 Influences of partner/husband on help-seeking Main theme to come out was that largely participants felt supported by their husbands.	Sub sub theme: 4.4.1 Restrictions Participants felt restricted to a certain extent about the topic area, and felt it was a topic not to be discussed. Although many had felt this they did inform their husbands.
<i>No of participants</i>	Supportive: 13 participants stated their husband supported them in health problems, and encouraged them to seek help. None: 1 participant stated her husband did not have any time for her at all.	Female problems: 7 participants stated they felt embarrassed talking about UI to their partner. Examination: 1 participant stated if they had to be examined by a male doctor, then they would need to ask their husband for permission.
<i>Illustrative quotes</i>	<p>'I do tell my husband things like he knows about diabetes and asthma, but this no (pg 7) Farhat</p> <p>'Lucky my husband supported me' (pg 30) Neelam</p> <p>'Influenced to go doctors by husband... 'I don't even have a sexual relationship with my husband' (pg 64) Nazia</p>	<p>If a woman seeks help from a man she needs her husbands permission (pg 19) Shahista</p> <p>'I was shy first to tell him because it is lady problem (ph 30) Neelam</p> <p>'About general health not about this problem... 'My husband told me examination by male is forbidden (pg 61) Nazia</p>

		<p>'Without my husband's permission... I cant, I don't want to go to hell, God will never forgive me' (pg 76) Hameeda</p> <p>'It's a woman thing so I felt horrible and dirty telling him' (pg 88) Sofia</p>
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Theme Four: Influences on help-seeking behaviour and decision-making

Sub theme: 4.5 Influences of religion on help-seeking behaviour	
Summary	<p>All participants stated if god gives you an illness he will surly give you a cure.</p> <p>Encourages: all participants stated God encourages you to seek help.</p> <p>Sends cure: all participants stated god will send a cure.</p>
No of participants	
Illustrative quotes	<p>'Allah states when you are ill he will send you a cure. You need to stay healthy to be religious (pg 6) Farhat</p> <p>'Islam tells you to go to the doctors when you need help and to make sure you get better' (pg 12) Naila</p> <p>'God has given you the knowledge to help yourself (pg 28) Khalida</p> <p>'God is testing me ... I have been rewarded... I just pray now...' Pray to God, things will et better' (pg 51) Nusrat</p> <p>'Islam says if you are unable to pray because of a illness than you need to go and see a doctor (pg 88) Sofia</p>
Sub sub theme: 4.5.1 Restrictions	
<p>The main restriction stated by participants was that is was forbidden for Muslim women to be examined by male doctors.</p> <p>Gender of doctor: 8 participants stated the gender of the doctor was a cause of concern and formed as a restriction, as women should not see male doctors.</p> <p>Husbands permission; 1 participant stated that if they had to seek help from a male it wouldn't be a problem, as much as gaining consent from their husband.</p> <p>None: 4 participants did not feel religion placed any restrictions.</p> <p>'If a woman seeks help from a man she needs her husbands permission (pg 19) Shagufa</p> <p>'We should not go to men doctors that is wrong...'Islam does not stop you going to the doctors (pg 47) Ghazala</p> <p>'I will not go against what my religion says, so I should not let a male doctor examine me' (pg 65) Nazia</p> <p>'I will ask for a woman, if one is not around I will not go I will have to live with it' (pg 65) Roshin</p> <p>'Islam says you should seek help from whoever is available' (pg 82) Ameena</p>	

Theme Five: Culture

Sub theme: 5.1 What culture means to them	
Summary	<p>Generally participants stated culture to them meant they way they have been bought up.</p>
No of participants	
Sub sub theme: 5.1.1 Lay aspects (personal beliefs)	
<p>Participants generally believed the examination by male was not right, and this was their belief.</p> <p>Examination: 6 participants stated they felt it was not right being examined by a male doctor.</p> <p>Girls should stay home: 2 participants stated girls</p>	
Sub sub theme: 5.1.2 Religious aspects (dress, customs)	
<p>Mix Reponses. Participants stated the traditional Muslim should be worn all the time by women.</p> <p>Cleanliness was the most important thing in Islam, and exposure and examination by males were forbidden.</p> <p>Examination; 8 participants stated women should not be examined by males.</p> <p>Hijab: 3 participants stated Muslim girls should always</p>	

	<p>Society: 4 participants stated the society they live in was their culture, people all having the same beliefs.</p> <p>Our people: 3 participants stated culture to them was their people.</p> <p>'Culture is our beliefs and practices that is what keeps people together (pg 6) Farhat</p>	<p>should stay at home and not work etc.</p> <p>Help from male doctors: 6 participants felt seeking helping from a male is not right at all.</p> <p>'personal problems should not be discussed outside the house (pg 14) Naila</p> <p>'You should dress in the traditional Asian dress and wear scarf, like my daughters (pg 22) Shahista</p> <p>'I know some people say you should not go to a man but why not, this is not what our Islam says anyway' (pg 28) Khalida</p> <p>'Would not go to male for female problems, it doesn't look right... 'I have been bought up and told girls should not work and they shouldn't... 'Every woman should have a son, it must be hard for your parents (pg 35) Ghazala</p>	<p>wear the hijab.</p> <p>Stay home: 2 participants stated girls should not work outside the house.</p> <p>No comment: 1 participant did not have any comment.</p> <p>'I should go to the doctors if I need help, not from men' (pg 14) Naila</p> <p>'Our dress how we act and things is related to our religion. Islam says a girl should cover her body we do (pg 20) Shagufta</p> <p>'Cleanliness is required in Islam' (pg 28) Khalida</p> <p>'Girls should not work (pg 35) Ghazala</p> <p>'Muslim woman should not expose her body to anyone (pg 49) Tayiba</p> <p>'My husband wanted me to change... I wear hijab now' (pg 68) Roshin</p> <p>'Without my husband's permission... I cant, I don't want to go to hell, God will never forgive me' (pg 76) Hameeda</p>
<i>Illustrative quotes</i>			

Theme Five: Culture	
<i>Summary</i>	<p>Sub theme: 5.2 Impact of culture on daily life</p> <p>Participants stated beliefs and practices taught by their parents was what kept them in a certain community. Participants also stated their parents had taught them to act appropriately in situations (like Muslim girls).</p>
<i>No of participants</i>	<p>Parents/teachings, Influential: 14 participants stated their parents were the most influential people in their lives and had bought them up like Muslim women.</p>
<i>Illustrative quotes</i>	<p>Sub sub theme: 5.2.1 Impact of society on daily life</p> <p>The overall theme was that participants felt their family was what they thought to be important and did not bother so much about the wider society. Although they felt living in an Asian area, they fit in well, due to similar religious beliefs and practices.</p> <p>Similar beliefs and practices: 5 participants stated they lived in predominantly Muslim areas, which made it much easier for them.</p> <p>Privacy: 2 participants stated it is very difficult to live your life without others looking in, they felt due to the area they lived in it was difficult. Participants further stated that they did not bother with the wider community.</p> <p>None: 6 participants stated the society they live in has no impact on their lives.</p> <p>'Whatever happens stays at home no one should no (pg 14) Naila</p>

	<p>wearing Asian clothes and things like that (pg 12) Naila</p> <p>'I do what my parents have taught me and I know I don't do anything wrong (pg 28) Khalida</p> <p>"As long as my family are happy, than I don't care what others think' (pg 62) Nazia</p> <p>'You at different at work at home with friends. So it does impact all of us (pg 82) Ameena</p>	<p>'If you want to live in any society you have to behave like they do to fit in (pg 19) Shagufta</p> <p>'I don't care what others think they were never around for me when I needed support (pg 26) Khalida</p> <p>'Asian families around here, it is nice people are just like you, people speak your language it is like a big family (pg 41) Ghazala</p> <p>'We have to live here so we are all the same, we dress eat sleep pray the same (pg 46) Tayiba</p> <p>'I don't bother about them anymore... I do what I want' (pg 57) Nusrat</p>
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Theme Five: Culture			
Summary	Sub theme: 5.3 Impact on management of UI	Sub sub theme: 5.3.1 Compliance	Sub sub theme: 5.3.2 Non compliance
	Participants felt the severity of their condition enabled them to seek help.	Compliance to treatment consisted of the ability to communicate with health professionals, which most of these women were unable to do. Knowledge was also related to compliance of treatment, which participants believed improved their overall health.	Lack of knowledge about UI increased lack of compliance. Most participants stated they were informed to complete regular exercises, which they believe did not help and required an operation.
No of participants	Severity: 6 participants felt the severity of their condition enabled them to seek help. Taboo: 2 participants felt due to the nature of the topic they do not discuss UI. Knowledge: 6 participants stated they did not feel they knew much about the topic to help themselves.	Communication: 4 participants stated the ability to communicate with professional help with compliance of treatment. Improvement: 2 participants felt compliance was related to improvement in condition. Gender of GP: 4 participants stated they would comply with treatment or seek help only if the professionals were female.	Lack of knowledge: 6 participants stated not knowing about the problem relates to non compliance. Operation: 4 participants stated they only wanted an operation, but were told to do exercises or take medication, which they believe did not help them. Communication: 4 participants stated not being able to communicate with the professionals themselves was a barrier when treatment was suggested.
Illustrative quotes	<p>'No one knows about this problem (pg 5) Farhat</p> <p>'I wanted a operation first but I have to try exercises (pg 40) Ghazala</p> <p>'We didn't get much information about it (pg 46) Tayiba</p>	<p>'get support (pg 20) Shahista</p> <p>'I just agree with what they say, I just want them to make me better (pg 40) Ghazala</p> <p>"I cant speak English who is going to listen to a Asian woman..."It can get worse, which I don't</p>	<p>'If I had to see a male doctor I would not go to the doctor (pg 15) Naila</p> <p>'Knowledge, no one tell you why it happens and that it is not normal (pg 20) Shagufta</p> <p>"Would not go to male for female problems, it</p>

<p>1. The first part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>2. The second part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>3. The third part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>	<p>4. The fourth part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>5. The fifth part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>6. The sixth part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>	<p>7. The seventh part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>8. The eighth part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>9. The ninth part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>	<p>10. The tenth part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>11. The eleventh part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>12. The twelfth part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>
<p>13. The thirteenth part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>14. The fourteenth part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>15. The fifteenth part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>	<p>16. The sixteenth part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>17. The seventeenth part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>18. The eighteenth part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>	<p>19. The nineteenth part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>20. The twentieth part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>21. The twenty-first part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>	<p>22. The twenty-second part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that proper record-keeping is essential for the company's financial health and for providing reliable information to stakeholders.</p> <p>23. The twenty-third part of the document outlines the specific procedures for recording transactions. It details the steps involved in the accounting process, from identifying the transaction to posting it to the appropriate ledger accounts.</p> <p>24. The twenty-fourth part of the document discusses the importance of reconciling the company's records with the bank statements. It explains how regular reconciliations help to identify and correct any discrepancies, ensuring that the company's records are accurate and up-to-date.</p>

		want that is why I decided to go to get myself sorted' (pg 82) Nazia	doesn't look right' (pg 37) Ghazala 'Tablets don't work (pg 43) Tayiba "I tried exercises but hey didn't work' (pg 52) Nazia "Fed up of taking tablets' feels don't work (pg 87) Sofia
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Theme Five: Culture				
	<i>Sub theme: 5.4 Impact on help-seeking behaviour</i> Mix response, many barriers were identified.	<i>Sub sub theme: 5.4.1 General (anxiety and circumstances)</i> Participants stated the gender of the doctor was a concern, as was the fear of not getting any better.	<i>Sub sub theme: 5.4.2 Traditional methods (Peer Saab)</i> All 14 participants stated they pray for better health, and God will be the only source that will send you a cure.	<i>Sub sub theme: 5.4.3 Conventional methods</i> Main theme here was that participants requested an operation as they believed this was the only option that will help. Many had been given medication and saw the physio, but did not comply with treatment, as they felt it did not work. Want operation: 7 participants requested operation and did not want to try exercise or medication. Physio: 9 participants had seen the physio, only 1 participant happy with exercise and felt an improvement. Other 8 were not happy. Nurse specialist: 14 participants had seen a nurse and were prescribed medication or were given pads, again participants were not happy. Peer Saab: 1 participant stated their peer Saab stated they needed an operation.
<i>Summary</i>				
<i>No of participants</i>	Communication: 2 participants communication played a major role in seeking help. Subject: 2 participants depending on what type of illness the were suffering from would matter. Severity: 4 participants stated the more sever the more likely participants were to seek help. Gender: 4 participants stated depending on whom they sow male or female would matter to them. N/A: 2 participants did not comment.	Gender: 3 participants were concerned whether the consultant would be male or female. Fear of examination: 9 participants felt anxious and worried if a male doctor would have to examine them. No improvement: 2 participants feared not getting better. Communication: 1 participant felt anxious, as she was unable to communicate in English. Previous bad experience: 1 participant feared previous experience would be repeated.	Praying: 14 participants the pray for better health, and believe strongly that a cure will be sent. Peer Saab: 2 participants had contacted their Peer Saab who informed them to either pray or seek help from doctors.	
<i>Illustrative quotes</i>	'examination by a male is wrong (pg 4) Farhat	"It would be nice seeing someone who can speak our own language, that is why I have to take my daughter with me' (pg 19) Shagufta	'I pray and ask for good health so I can look after my children and my house (pg 10) Naila 'Peer told me I can pray if I leak but I don't think this is right you have to be clean and do	'I have had the operation but I still wear pads (pg 5) Farhat 'I went to doctor because I could not do it anymore (pg 27) Khalida

		<p>'I am scared just in case the same doctor is there (pg 22) Shahista</p> <p>'What if I don't get better... 'We should always pray because when we do god sends us a cure...' God has given me the knowledge to go out and find help to make me better (pg 31) Neelam</p> <p>'I can understand why some people don't want to see male doctors, its not right but if you need help does it matter who you see' (pg 71) Roshin</p> <p>'I see [SH] because I don't have a choice ... if I want to get better does it matter who I see' [severity]... 'My husband would never let me see a male doctor for this' (pg 77) Hameeda</p>	wadu before praying (pg 20) Shagufta	<p>'I do exercises and wear pads that is what I have been told by the nurse and physio (pg 33) Neelam</p> <p>'I have been told to do exercises but I don't want that I want a operation to get me better (pg 75) Hameeda</p>
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Theme Six: Religion		
Summary	<p>Sub theme: 6.1 Quran 'what is actually said</p> <p>Participants stated it was forbidden to seek help from male doctors and this was stated in the Quran.</p>	<p>Sub sub theme: 6.1.1 Hadith (prophets teachings)</p> <p>Participants stated the prophet has also stated that examination by a male doctor is forbidden. However, if not female is available a woman should seek the permission of her husband and be accompanied by him.</p>
No of participants	<p>Forbidden: 5 participants stated it is stated in the Quran that Muslim women should not see male doctors.</p> <p>Not forbidden: 7 participants stated there are no restriction placed on this.</p> <p>Encourages: 5 participants stated Islam encourages people to seek help.</p>	<p>Male professionals: 7 participants stated if no female doctor was available the prophet has stated that they can see male doctor with the permission of their husband.</p> <p>Strictly forbidden: 7 participants stated they should under no circumstances should a woman see a male doctor.</p>
Illustrative quotes	<p>'It is said in the Quran that a man should not examine a woman (pg 4) Farhat</p> <p>'To better your health if a male is only available then so what, you need help' (pg 4) Farhat</p> <p>'Its not right for a woman to see a man, it shouldn't be done in Islam, its</p>	<p>'To better your health if a male is only available then so what, you need help' (pg 4) Farhat</p> <p>'Islam also says if you are unable to pray because of a illness than you need to go to the doctors' (pg 77) Hameeda</p>

	<p>wrong' (pg 13) Naila</p> <p>'Muslim girls should not work. It is not right them mixing in with other men (pg 35) Ghazala</p> <p>'Islam says we should go to the doctors if it is getting in the way of you and praying...' Good and bad is from Allah and we need to leave everything to Him (pg 69) Nazia</p> <p>'The only time this can be done if is your health becomes really bad and there is no woman doctor (pg 86) Sofia</p>
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Theme Six: Religion			
	Sub theme: 6.2 People's interpretation	Sub sub theme: 6.2.1 Scholars of Islam	Sub sub theme: 6.2.2 Customs and practices
Summary	Mainly participant felt they should not seek help from male professionals, and was stated in the Holy books.	Islamic teachings were gained from Molvis, Imam, Peer Saab and their parents.	The main theme emerging here were that women should not seek employment or education and should stay at home and the second theme was the wearing of the hijab.
No of participants	Not read: 3 participants had stated they had not read things themselves but were informed by parents and husband. Women restricted: 9 participants stated they were not able to seek help from men professional, although many had without their partners knowing. Forbidden: 2 participants stated it was strictly forbidden for women to see male doctors.	Molvīs: 12 participants stated their teachings about practices of Islam were gained from Molvi's. Imam: 7 participants stated Imam were the ones that increased their knowledge about Islamic teaching. Peer Saab: 1 participant consulted her peer if she was unsure about things. Changed: 3 participants stated these people would change things to suit themselves.	Hijab: 3 participants stated Muslim women should wear the hijab or scarf, as this tells people you are Muslim and it is their dress. Mixing: 4 participants stated women should not work outside the house. Permission: 2 participants stated they would need to gain permission from their husband prior to examination. Examination: 5 participants stated examination by male should not be done.
Illustrative quotes	<p>'Have been told that women should not seek help from male, I have not read it myself' (pg 4) Farhat</p> <p>'It is hard for women to get out and find out' (pg 20) Shagufta</p> <p>'People think women cannot do anything in Islam (pg 24)' Shahista</p> <p>'I know some people say you should not go to a man but why not, this is not what our Islam says anyway' (pg 28) Khalida</p>	<p>'People that are high like Imams and molvis tell us things about Islam but sometimes they change things (pg 31) Neelam</p> <p>'Islam says we should go to the doctors if it is getting in the way of you and praying' (pg 65) Nazia</p> <p>'These big men change it to suit themselves...' 'The true Islam is in the Hadith and the Quran I live my life the way Allah wants me to (pg 75) Hameeda</p> <p>'We are taught about Islam in mosques by Imam and Molvis. There are different sects of Islam so</p>	<p>'Women should cover their head and stay at home (pg 3) Farhat</p> <p>'People say you should only see women but if they are going to help then does it matter who we see (pg 23) Shahista</p> <p>'If I think something that I have been told is wrong or right, I always ask my husband (pg 31) Neelam</p> <p>'Muslim girls should wear Asian clothes but here you lot don't that is wrong god will punish you lot (pg 35) Ghazala</p>

	<p>Islam does not say this but my parents have taught me this (pg 47) Tayiba</p> <p>'My parents and husband told me examination by male is wrong...' I cant read Urdu so I ask my husband and he tells me (pg 61) Nazia</p>	<p>people have made their beliefs to fit there lives (pg 84) Ameena</p> <p>'There are that many people that say you should do this and not that. you should do what Islam tells you (pg 86) Sofia</p>	<p>'A Muslim woman should not let a man examine her (pg 47) Tayiba</p> <p>'Without my husband's permission... I cant, I don't want to go to hell, God will never forgive me' (pg 76) Hameeda</p> <p>'My jeans don't make me less of a Muslim' (pg 80) Ameena</p>
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Theme Six: Religion			
Sub theme: 6.3 How they describe religion			
Summary	Participants described their religion in three ways: peaceful, pure and their life.	Sub sub theme: 6.3.1 What religion means to them All participants stated being Muslim was part of their identity and would describe themselves as Muslims.	Sub sub theme: 6.3.2 How others perceive their religion Mainly participant's views were that they did not care what other people thought about them. Concern about people finding out about Islam for themselves should be considered before passing judgements.
No of participants	Peaceful: 6 participants stated their religion to be peaceful. Pure: 5 participants stated their religion was pure. Their life: 4 participants stated Islam was their life. Five pillars: 1 participant described the five pillars of Islam.	Identity/Muslim: 11 participants described Islam and being Muslim as their identity. Belief in one God and prophet: 3 participants stated having the belief in Allah and the prophet Muhammed was their religion.	I don't care: 8 participants stated they did not bother with what others thought. Read: 5 participants stated people should inform themselves about Islam and not judge everyone with the same brush. Terrorists: 4 participants felt people viewed all Muslims as terrorists. Women oppressed: 1 participant stated other think women in Islam are oppressed.
Illustrative quotes	<p>'Peaceful and pure religion (pg 6) Farhat</p> <p>'Five pillars of Islam, Iman namaz roza zakat haji (pg 7) Farhat</p> <p>'Islam is my life, it is so peaceful (pg 19) Shagufta</p> <p>'Islam to me is what keep my mind peaceful and that is how I describe my religion peaceful (pg 73) Hameeda</p>	<p>'I am a Muslim and that is my identity (pg 3) Farhat</p> <p>'Muslim is believing in one God and Muhammed last prophet that is a Muslim (pg 55) Nusrat</p>	<p>'If people have a problem with Islam then maybe they should find out about for themselves what Islam is about (pg 6) Farhat</p> <p>'They don't like us because we are Muslims (pg 24) Shahista</p> <p>'People think because we are Muslim women we cant do anything, then they should go to the Islamic countries and see women do more than men (pg 28) Khalida</p>

Theme Six: Religion		
Sub theme: 6.4 How religion impacts on daily life		
Summary	Participants all felt religion/Islam was a part of their	Sub sub theme: 6.4.1 Benefits of practices Benefits of religion consisted of the closeness to
		Sub sub theme: 6.4.2 Restriction of religion Participants felt examination by a male was forbidden

	life.	God and the togetherness of the communities they lived in.	in Islam, although many had been examined by male professionals. Examination forbidden: 7 participants stated although these participants had sought help and felt better; they also believed they had gone against what their religion asks from them. Permission: 3 participants stated it was not forbidden, but they would need to ask permission and be accompanied for examinations by their husbands. None: 2 participants did not feel there were any restrictions. N/A: 2 participants did not comment.
<i>No of participants</i>	Life: 10 participants stated Islam was part of their lives. Five pillars: 2 participants recited the five pillars of Islam. Restriction: 2 participants stated due to their UI problems they were unable to perform or worship God.	Closeness: 7 participants stated they felt close to God which meant the more they worshipped the more likely they would be better off. Togetherness: 7 participants stated as their wider community were mainly Muslim they felt achievement that people around them had similar beliefs.	Examination forbidden: 7 participants stated although these participants had sought help and felt better; they also believed they had gone against what their religion asks from them. Permission: 3 participants stated it was not forbidden, but they would need to ask permission and be accompanied for examinations by their husbands. None: 2 participants did not feel there were any restrictions. N/A: 2 participants did not comment.
<i>Illustrative quotes</i>	<p>'Whatever I do I do it with my religion in mind (pg 6) Farhat</p> <p>'I try and do everything I can as what is written. But the worse thing is since I started having this problem I have not prayed (pg 22) Shahista</p> <p>'I have started to pray five times a day. I started covering my body' (pg 68) Roshin</p> <p>'Whatever I do I thank god for even if I am getting punished now I wont after death (pg 75) Hameeda</p>	<p>Everyone has the same beliefs and stick together (pg 6) Farhat</p> <p>'I feel closer to my God when I pray and I am sure whoever does feels the same (pg 27) Khalida</p> <p>'Islam brings people together who have same beliefs and practices, community becomes even bigger (pg 87) Sofia</p>	<p>'If a woman seeks help from a man she needs her husbands permission (pg 19) Shagufta</p> <p>'Islam does not stop you from doing things, it tell us what is right and wrong. Going to a man doctor is not wrong, but people say this is religion and it is not (pg 27) Khalida</p> <p>'Muslim woman should not expose her body to anyone (pg 49) Tayiba</p> <p>I would juts put up with whatever problem I had' (pg 47) Tayiba</p> <p>'I will ask for a woman, if one is not around I will not go I will have to live with it' (pg 65) Roshin</p> <p>'I will not go against what my religion says, so I should not let a male doctor examine me...' 'I know its written' (pg 61) Nazia</p>

Theme Six: Religion	
	Sub theme: 6.5 Their role as Muslim women
Summary	Participants stated their role as Muslim women was to look after their family and pray and worship Allah.
No of participants	Same as man: 12 participants stated their role in Islam was the same as a woman's, to

	man's, to worship Allah. Stay at home: 2 participants stated their role was to stay at home and look after the family that is what their religion taught them.	worship Allah. Stay at home: 2 participants stated men's role was to earn and provide for the family.
Illustrative quotes	<p>"To look after my family and sow them the right path (pg 6) Farhat</p> <p>"The same as a man in Islam (pg 15) Naila</p> <p>"Both men and women are equal, yes a women is more likely to cook and clean and man more likely to work (pg 23) Shahista</p> <p>"To stay in the house and look after children (pg 34) Ghazala</p> <p>"To pray and worship Allah (pg 67) Roshin</p>	<p>"The same as a woman (pg 15) Naila</p> <p>"Both men and women are equal, yes a women is more likely to cook and clean and man more likely to work (pg 23) Shahista</p> <p>"The same as women's to worship Allah (pg 67) Nazia</p> <p>"There are not differences in front of Allah but men make these differences (pg 73) Hameeda</p>

Theme Seven: Communication and language		
	Sub theme: 7.1 Ability to speak English	Sub sub theme: 7.1.1 Unable to communicate in English
Summary	Mainly participants could either speak English or could not. Majority had never learnt to speak English.	Mainly participants could either speak English or could not. Majority had never learnt to speak English. One participant felt if she speaks English people would laugh at her.
No of participants	No: 8 participants could not speak English at all. Yes, not good: 4 participants could speak English but stated was not so good. Yes: 2 participants had no problems speaking English at all.	No: 8 participants could not speak English at all. Yes, not good: 4 participants could speak English but stated was not so good. Yes: 2 participants had no problems speaking English at all.
Illustrative quotes	<p>"Cannot speak English well (pg 18) Shahista</p> <p>"I learnt English in India but it is different to how you lot speak (pg 30) Neelam</p>	<p>"I cant speak English (pg 17) Shagufta</p> <p>I have never learnt to speak English, picked up little bits from my children (pg 18) Shahista</p> <p>"I cant speak English proper so people don't have time for you' (pg 85) Sofia</p>

Theme Seven: Communication and Language			
	Sub theme: 7.2 The use of translators	Sub sub theme: 7.2.1 Translated documents	Sub sub theme: 7.2.2 Use of family members
Summary	Participants had never used hospital translators.	Participants had seen information in other languages.	Mainly participants had used female family members through consultations.
No of participants	Never used: 12 participants had never used a translator.	Seen and read: 5 participants were provided with information about UI in	Daughter: 5 participants take their daughters with them to all the
			Sub sub theme: 7.2.3 Other means of communication The two participants that did comment about other means of communication, was the fact they helped their parents with communication and were used as translators. Helped others: 2 participants either helped their parents or others with communication.

	Unaware of service: 1 participant was unaware of the translation service. Awaiting: 1 participant had to delay her operation as consultant was waiting for a translator to be present.	Urdu and felt it was written well enough for them to understand. Seen but not read: 5 participants had seen information in other languages, but not read. Not seen: 1 participant had not seen any information in Urdu. Unable to read Urdu: 3 participants could not read Urdu at all.	consultations. Daughter in law: 4 participants use their daughter in laws for communication. Sister in law: 1 participant used the help of her sister in law. None: 4 participants did not use any family members, for various reasons. Mainly because they could speak English well, or because they did not have anyone available.	N/A: 12 participants did not comment.
<i>Illustrative quotes</i>	'I have never used hospital people (pg 5) Farhat 'Not from the hospital can you get people there (pg 18) Shagufta	'I have seen things in Urdu and other languages but I have not really took any (pg 6) Farhat 'I have been given some about UI (pg 12) Naila 'My Urdu is better, I can understand this information you gave me. The doctors and nurses gave me information in Urdu (pg 29) Khalida 'Never seen any documents in Urdu (pg 62) Nazia 'I have seen them and they are well written especially for those women who cannot read or understand English (pg 69) Roshin	'I take my daughters with me because I cant speak English (pg 5) Farhat 'I use to take my sister in law before but now I would go myself I don't want others to know about my problems (pg 14) Naila	'I do try and help those that cannot speak Urdu, but my Urdu is pathetic I am sure they laugh at me (pg 79) Ameena

Theme Seven: Communication and language

	Sub theme: 7.3 Compliance		Sub sub theme: 7.3.1 Non compliance
<i>Summary</i>	Compliance to treatment was closely related to overall improvement.		Non-compliance was related to no improvement to health.
<i>No of participants</i>	Improvement: 4 participants stated improvement to health was related to compliance of treatment. Understanding/knowledge: 3 participants stated understanding about the subject was related to compliance. Communication: 4 participants felt the ability to communicate was related to compliance.		No improvement: 4 participants stated they did not complete exercise or took medication prescribed as they felt they did not work and wanted operation. Lack of knowledge: 1 participant stated their lack of knowledge about the condition was the cause of them not complying. Busy lifestyle: 3 participants felt they did not comply with exercise because of their busy lifestyle.

	Severity: 1 participant stated the severity of the condition forced them to comply with treatment.	Wanted operation: 4 participants only wanted an operation.
<i>Illustrative quotes</i>	<p>'I had operation that is what I wanted (pg 5) Farhat</p> <p>'It can get worse, which I don't want that is why I decided to go to get myself sorted' (pg 82) Ameena</p>	<p>'They told me to do exercises which don't work... 'It is hard for women to get out and find out' (pg 20) (knowledge) Farhat</p> <p>'Bad past experiences (pg 19) Shahista</p> <p>'Exercises didn't work (pg 52) Tayiba</p> <p>'I cant speak English who is going to listen to a Asian woman' (pg 66) Nazia</p> <p>'I never took the tablets [non compliance]' (pg 74) Hameeda</p>

Theme Seven: Communication and language			
	<i>Sub theme: 7.4 Communication with professionals</i>		
<i>Summary</i>	Overall participants could not speak English well.	<i>Sub sub theme: 7.4.1 GP</i>	<i>Sub sub theme: 7.4.2 Nurses</i>
<i>No of participants</i>	Inability: 8 participants could not speak English at all. Try hard: 2 participants stated they try hard to speak to English. Speaks English: 4 participants spoke English well.	All participants stated they GP's spoke Urdu. Urdu: 14 participants stated their GP spoke English.	Generally, participants stated they try to communicate with nurses. Try to communicate: 6 participants try to communicate with practice nurses. Takes daughter: 4 participants take their daughters with them. Can't speak: 3 participants felt they could not communicate with nurses at all.
<i>Illustrative quotes</i>	<p>'They all speak English and I cant so I have to take my daughter with me (pg 5) Farhat</p> <p>'I will ask for a woman, if one is not around I will not go I will have to live with it' (pg 65) Nazia</p> <p>'I cant speak English proper so people don't have time for you' (pg 85) Sofia</p>	<p>'My GP is Muslim and he can understands me (pg 4) Farhat</p> <p>'They can speak Urdu. So it makes it easier for me but they don't care (pg 76) Hameeda</p>	<p>'I always take my daughters to the physio, when I see her, because she speaks English' (pg 7) Farhat</p> <p>'Previous experience was not good that is why now I take my daughter with me (pg 20) Shahista</p> <p>'I take my daughter in laws with me I cant speak English and most of them are English (pg 46) Tayiba</p>

Theme Eight: Media	
Summary	<p>Sub theme: 8.1 Influences of media on health Participants felt general health issues are discussed in the media and they have a positive influence on health.</p> <p>General health: 7 participants felt the media showed a lot of things about health issues.</p> <p>No impact: 7 participants stated it does not make any difference what is shown in the media.</p> <p>Yes telly show a lot of things about health, like eating and exercises (pg 29) Khalida</p> <p>God yes media has a great influence on our health as a nation there is not just the telly, but you have leaflets that are posted through your doors, there is newspapers etc (pg 83) Ameena</p>
No of participants	General health: 7 participants felt the media showed a lot of things about health issues.
Illustrative quotes	<p>'No one tells you about this, if we knew I think we wouldn't let it get this bad' (pg 20) Shagufta</p> <p>'I have not seen anything about UI, just what my doctor has told me (pg 19) Shahista</p> <p>'I have not seen anything about this problem, but these pads are shown on telly (pg 29) Khalida</p> <p>'You should not talk in public about this anyway it is private (pg 61) Nazia</p> <p>'Leaking urine is not like having diabetes or asthma, you probably get sympathy for that' (pg 70) Roshin</p>

Theme Eight: Media	
Summary	<p>Sub theme: 8.2 Influences of media on religion Islam is perceived in a negative image, and is on telly for the wrong reasons.</p> <p>Negative image: all 14 participants felt Islam was on the telly for wrong reasons and Muslim was viewed as violent people.</p> <p>Negative influence (pg 9) Naila</p> <p>There is a lot about Islam on telly for the wrong reasons (pg 29)</p>
No of participants	<p>Sub theme: 8.2.1 Benefits There were no benefits reported however 2 participants felt people were more aware of Islam and Muslims.</p> <p>None: 10 participants stated there were no benefits to the way Muslims are portrayed in the media.</p> <p>Awareness: 4 participants even if was for the wrong reasons people are increasing their knowledge about Muslim and Islam.</p> <p>There is no benefits (pg 19) Shahista</p> <p>There is none. But on the Asian channels they teach you about Islam</p>
Illustrative quotes	<p>Sub theme: 8.2.2 Barriers Participants stated due to the terror attacks they felt scared to leave their homes, and further that not all Muslims are the same.</p> <p>Scared: 6 participants stated since the terror attacks they felt nervous and anxious when leaving their homes.</p> <p>Not all the same: 8 participants stated not ever Muslim is the same. And they should not be targeted just because a hand full of so called Muslims harmed other people.</p> <p>'We cannot carry on with our normal lives without people thinking wrong about us (pg 7) Farhat</p>
	<p>Sub sub theme: 8.2.3 Views of society Participants overall felt they were viewed as terrorists.</p> <p>Terrorist: 14 participants stated others viewed ever Muslim as a terrorist.</p> <p>'People think we are all bad, but other religions have bad people but no one says anything (pg 7) Farhat</p>

	<p>Khalida</p> <p>'People everywhere are talking about Islam but not in the good way (pg 62) Nazia</p> <p>'They have totally perceived our Islam wrong. But then again we are only shown and told what people want us to know (pg 83) Ameena</p>	<p>which is good (pg 32) Neelam</p>	<p>'I am scared when I see a white person especially boys (pg 61) Nazia</p> <p>'It makes it hard for us to live in the UK (pg 88) Sofia</p>	<p>'We are looked at in the wrong way not everyone is the same, fighting happens everywhere in the country about different religions (pg 29) Khalida</p> <p>People are narrow minded. What about when other people cause problems no one says anything to them (pg 39) Ghazala</p> <p>'I am not bothered what others think why don't people really look into the background to the 9/11 and find out who it was (pg 69) Roshin</p> <p>'People don't see you they see your skin colour, what about all the attacks from the Irish and others were the call Christian terrorists (pg 83) Ameena</p>
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Theme Eight: Media				
<i>Summary</i>	Sub theme: 8.3 Influence of media on culture Overall participants felt the media did not affect their culture.	Sub sub theme: 8.3.1 Dress The general idea was that the hijab or head scarf formed a part of the Muslim women's identity and was their traditional dress.	Sub sub theme: 8.3.2 Male domination Participants generally believed there was no such concept of male domination.	
<i>No of participants</i>	None: 12 participants felt culture and media did not affect each other. Oppressed: 2 participants stated the media views Muslim women as oppressed.	Traditional/identity: 9 participants felt their clothes formed a part of their identity and their religion. Don't care: 3 participants stated they did not care what others thought about their clothing. Jeans: 1 participants stated to her clothing did not identify you as a Muslim or not.	No such thing: 11 participants did not agree and stated there was no such thing. Equality: 3 participants stated both were equal. Domination: 2 participants felt there was male domination.	
<i>Illustrative quotes</i>	'People see Muslim women as soft and stuck in the house that is not true (pg 54) Nusrat <p>'Who are these people to judge us' (pg 71) Nazia</p>	'No one has said anything to me about me clothes, my children also wear the same (pg 8) Farhat <p>'That is not true everyone is equal (pg 7) Naila</p> <p>'They think we should change to fit in, but this is our religious clothing (pg 20) Shahista</p> <p>'The traditional dress for us is scarf and Asian dresses, but you lot here don't wear it (pg 33) Neelam</p>	'That is not true everyone is equal (pg 7) Farhat <p>'Its not domination, it is they way we have been bought up (pg 7) Naila</p> <p>'There is no male or female domination this is just made up (pg 23) Shahista</p> <p>'Yes men can do what they want (pg 51) Nusrat</p>	

		<p>‘Here we have to change as long as you are not showing your body I don’t think you are doing anything wrong (pg 52) Nusrat</p> <p>‘My jeans don’t make me less of a Muslim’ (pg 80) Ameena</p>	<p>‘Without my husband’s permission... I cant, I don’t want to go to hell, God will never forgive me’ (pg 76) Hameeda</p>
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Theme Nine: Family

	Sub theme: 9.1 Importance of family		
<i>Summary</i>	After religion participants family was the most important thing to them.	Sub sub theme: 9.1.1 Over self	
<i>No of participants</i>	Very important: 13 participants all felt strongly about their family. Don’t have anyone: 1 participant did not have any family.	Mainly participants stated their family came before their own health, however some stated health before family, and as if they were unwell they would not be able to look after them.	
<i>Illustrative quotes</i>	<p>‘family is my life (pg 13) Naila</p> <p>‘My family are very important to me they are only thing I have (pg 17) Shagufta</p> <p>‘My family are important after my religion, its because of my faith I have my child (pg 79) Ameena</p>	<p>Family first: 10 participants stated their family came even before their own health.</p> <p>Health first: 4 participants stated their health was important. If unwell they would not be able to care for their family.</p> <p>‘family come first (pg 5) Farhat</p> <p>‘I have to be healthy to look after them, so my health is important to me (pg 17) Shagufta</p> <p>‘Family come first after religion (pg 62) Nazia</p>	

Theme Nine: Family

	Sub theme: 9.2 Views of elders		
<i>Summary</i>	Elders views were that of parents and in laws, which participants stated were very important to them.	Sub sub theme: 9.2.1 Views of partner	
<i>No of participants</i>	Important: 13 participants stated the views of the elders were very important, and they did as they were told too. Did not argue. None: 1 participant stated her elder’s views were not important to her, because due to them she is in this situation now (married and unhappy).	Again participants stated the views of their partners were as important as their parents.	
<i>Illustrative quotes</i>	<p>‘‘examination by a male is wrong (pg 4) Farhat</p> <p>‘My family’s views are important. they influence me a lot (pg 12) Naila</p> <p>‘I have always done as they have told me (pg 16) Shagufta</p>	<p>Important: 8 participants stated after their parents views their husbands views was as important.</p> <p>Supportive: 3 participants stated their husbands were very supportive, and their views mattered as much as theirs mattered to them.</p> <p>Permission: 1 participant stated she would always gain the permission of her husband, before doing anything at all.</p> <p>None: 1 participant stated her partner did not have time for her and vice versa.</p> <p>‘‘My husband encourages me to do things. His views are important to me (pg 9) Naila</p> <p>‘My husband views are important and mine are to him (pg 66) Nazia</p> <p>‘Without my husbands permission I don’t do anything’ (pg 76) Hameeda</p>	

	<p>'I have been bought up and told girls should not work and they shouldn't go outside the house, and I listened to them (pg 35) Neelam</p> <p>'I have done whatever my elders have said and did not argue one bit (pg 70) Roshin</p>		'His views are very important to me and he supports me well in everything I do (pg 80) Ameena
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Theme Nine: Family			
Summary	Sub theme: 9.3 Extended family (impact of) All participants felt a sense of belonging and togetherness with their families.	Sub sub theme: 9.3.1 Benefits Generally participants felt supported.	Sub sub theme: 9.3.2 Restrictions Lack of privacy and arguments was the main restrictions noted by participants.
<i>No of participants</i>	<p>Togetherness: 8 participants said they felt they belonged and have a sense of togetherness.</p> <p>Do not get along with them: 6 participants stated they did not get along with their extended family, this related to their husbands side of the family.</p>	<p>Support: 12 participants felt supported by the extended family.</p> <p>None: 2 participants did not feel any benefits.</p>	<p>Lack of privacy: 6 participants stated living in the extended family meant they had no privacy.</p> <p>Arguments: 4 participants stated they are more arguments when people all live tighter.</p> <p>None: 4 participants did not comment.</p> <p>Order: 1 participant felt they had no time for themselves as they had to look after the rest.</p>
<i>Illustrative quotes</i>	<p>'Most of my husband's family is here. When I came we all lived together, it was nice (pg 31) Neelam</p> <p>'Nice we all live around, but each evening we all meet up here at my mums (pg 71) Roshin</p>	<p>'there was more support (pg 10) Naila</p> <p>'We all live together, my children look after me (pg 62) Nazia</p> <p>'You have more support you don't have to turn to a stranger to talk about things (pg 71) Roshin</p>	<p>'Living in the big house was a problem, I could not be myself (pg 10) Naila</p> <p>'They use to tell me what to do and when to do it, but not anymore (pg 28) Khalida</p>

Theme Nine: Family			
Summary	Sub theme: 9.4 Employment opportunities Overall participants were unable to seek employment due to the restriction placed on them through their parents or husband.	Sub sub theme: 9.4.1 Educational opportunities Same as employment. Participants were unable to seek education as their parents beliefs were that girls should stay at home.	
<i>No of participants</i>	<p>No never: 11 participants were unable to seek employment either because parents did not allow it or husband.</p> <p>Worked: 2 participants had to work to support family as husband had left them. 1 participant worked full time.</p>	<p>No: 8 participants did not get the opportunity.</p> <p>Basic education: 3 participants gained the basic education either in Pakistan or until high school in the UK.</p> <p>ESOL classes: 2 participants sought permission from their parents to attend ESOL classes.</p> <p>Yes: 1 participant had the opportunity but could not be bothered.</p>	
<i>Illustrative quotes</i>	<p>'I have never worked and nor have my daughters my husband does not like it (pg 6) Farhat</p> <p>'I have told my girls to work and they should we didn't get chance (pg 50) Nusrat</p>	<p>'I didn't get the chance, but I have sent my younger daughter to university (pg 2) Farhat</p> <p>'I didn't have the chance but my eldest daughter is a teacher, the other is doing law (pg 49) Nusrat</p> <p>'There is no point educating girls (pg 62) Nazia</p>	

			'I never went to school because my parents would not allow it, they have always said girls should stay at home (pg 84) Sofia
Theme Nine: Family			
Summary	Sub theme: 9.5 Their role as women in the family		
No of participants	Participants felt their role as women was to look after their family. Primary role: 10 participants stated their role was to stay at home and look after their family (children, husband and house). Same as man's: 3 participants stated their role was the same as a man's in their family. Don't get on: 1 participant did not get on with her husband.	Sub sub theme: 9.5.1 Partner's role in family Primary role of men in the family was to provide and earn. Provide and earn: 6 participants stated their husband roles was to ear and provide for the family. Same as women: 3 participants stated their husband's role was the same as theirs. Died: 2 participants stated their husbands had died. Although their role was to provide for the family. Don't know: 2 participants stated they had no idea was their partner's role was in their family as they did not get on.	
Illustrative quotes	'Look after family (pg 7) Farhat 'To have children, look after husband and provide for them (pg 6) Naila 'To look after children and bring them up in the right way. The right way is the Islamic way (pg 30) Khailda 'As women I suppose we are taught our role is to look after the family and husband, not work and learn how to look after your house (pg 69) Roshin	'To provide for the family and look after us (pg 6) Farhat 'He should be the one to go out the house to earn and provide for us (pg 69) Roshin 'We are both equal in everything we do he does the house work with me, we both work outside the house (pg 80) Sofia	

Theme Ten: Cultural differences			
Summary	Sub theme: 10.1 Their upbringing All participants stated their upbringing either in the UK Pakistan or India was very strict and more Islamic.		
No of participants	Very strict: all participants stated their upbringing was strict, although 1 participant stated she was able to go to further education. Islamic based: all participants stated their upbringing was very Islamic.	Sub sub theme: 10.1.1 Upbringing in home country Mix responses. Girls stay at home: 5 participants girls over there had to stay home and learn how to look after the house. The chance for education or employment was not available (older participants). Much better life there: 4 participants felt it was a much better life in India or Pakistan (older participants). No respect for elders here: 2 participants felt there was more respect for people over there. Our people there: 4 participants stated the difference was that our people were over there. We are strangers in the UK.	Sub sub theme: 10.1.2 Differences in upbringing Mainly negative responses were given about their life in the UK. The only positive was that girls had more freedom for education and employment. Did what we were told: 3 participants stated children did as they were told in their own countries. Freedom there: 2 participants felt they had more freedom there. Freedom for girls here: 9 participants felt everyone here is treated equally. No difference: 1 participant felt there was no difference in the countries.

		Not our country: 3 participants felt UK was not there country.	
<i>Illustrative quotes</i>	'Very strict girls have to stay home and look after the rest of the family (pg 18) Shagufta	<p>'We did exactly as we were told and never argued (pg 2) Farhat</p> <p>'Much better there, I had a lot of freedom (pg 14) Naila</p> <p>'Children now a days don't have any respect for their elders just do what they want (pg 18) Shagufta</p> <p>'Everyone is the same (pg 31) Neelam</p>	<p>You try to put things on children but they don't listen cause they are mixed in to these people here (pg 1) Farhat</p> <p>'Girls had more freedom there (pg 13) Naila</p>

Theme Ten: Cultural difference			
	Sub theme: 10.2 Influence on the lives of their children		
<i>Summary</i>	Participants stated they would encourage their traditional practices which were taught to them to their children.	Sub sub theme: 10.2.1 Practices	Sub sub theme: 10.2.2 Parents
<i>No of participants</i>	<p>Traditional ways: 4 participants stated they would continue with their traditional values and also teach their children the same.</p> <p>Encourage children: 6 participants stated they would encourage their children to mix in get education and employment.</p> <p>Mixed now: 3 participants stated their children did not carry out traditional practices and they felt their children had taken the western view on life.</p> <p>No children: 1 participant did not have nay children.</p> <p>'They are only young now. I will teach them our ways too (pg 13) Naila</p>	<p>Mainly participants continued with the traditional practices and encouraged their children too.</p> <p>Continued: 13 participants lived their lives as they did in Pakistan.</p> <p>UK: Participants that were born in the UK also turned to traditional ways, only one participant did not continue all the traditional, for example continued working etc.</p>	<p>General theme was that participants did exactly as was asked by their parents.</p> <p>Did exactly what was asked: 12 participants stated they did exactly what was told and never argued. Times have moved on: 1 participant stated times have moved on from what our parents have taught us.</p> <p>Encouraged to mix: 1 participant stated her parents encouraged her to mix but also maintained the religious side too.</p>
<i>Illustrative quotes</i>	<p>'I have encouraged my children to work get education you need to work in this country to live (pg 23) Shahista</p> <p>'The way my parents bought me up that is the way I will bring my children up (pg 31) Neelam</p> <p>'You lot that have been born here think you are like them (pg 62) Nazia</p>	<p>'I have continued to live my life like I did in Pakistan (pg 7) Farhat</p> <p>'My girls work, but when they get home the get changed into our clothes and live like Pakistani girls should... You don't forget your roots, we are strangers in this country (pg 23) Shahista</p> <p>'I got married because my dad wanted to, I moved here because my husband wanted to. I have always respected those that I am suppose to (pg 73) Hameeda</p>	<p>'What ever my parents told me I did (pg 9) Naila</p> <p>'We took care of our elders and listened to everything they told us (pg 17) Shagufta</p> <p>'whatever they said we did not argue (pg 25) Shahista</p> <p>'Times have moved on from what our parents taught us (pg 50) Nazia</p> <p>'My parents never forced us to wear Asian clothes or anything... 'My parents let us to do what we wanted as long as we lived the way a Muslim is suppose to (pg 80) Ameen</p>

Theme Ten: Cultural difference				
	Sub theme: 10.3 Country of birth			
Summary	Sub sub theme: 10.3.1 Arrival in the UK	Sub sub theme: 10.3.2 Differences in country	Sub sub theme: 10.3.3 Health care in own country	
	Overall participants were born outside the UK.	Participants had been in the country from 6 years to 42 years. 1 participant was born in the UK.	Difference between people that had been in the UK for some time or born here than for those that had more recently come into the UK.	The difference between the health cares was that the health service abroad was not free. Participants also felt they got to choose who they show and service was much quicker.
No of participants	Pakistan: 10 participants originated from Pakistan. India: 1 participant was from India. Kenya: 1 participant originated from Kenya. Malawi: 1 participant originated from Malawi but had been in the UK since the age of 2. UK: 1 participant was born and bought up in the UK.	0-10 years: 3 participants fell in this category. 10-20 years: 2 participants. 20-30 years: 2 participants. 30 – 40 years: 5 participants. 40 years and over: 1 participant. Born in the UK: 1 participant.	Equality: 2 participants stated boys and girls are equal here. Hard: 3 participants stated it was hard for girls here. Settle: 3 participants felt it was hard for them to fit into and settle in the UK. More freedom: 1 participant felt there was much more freedom for women in the UK. Difference: 2 participants felt there was no difference.	Pay: 9 participants stated they would have to pay for health care in their own countries. Choice: 7 participants felt you had a choice of who you saw in their countries. No waiting list: 1 participant stated people are seen much quicker in their own countries.
Illustrative quotes				
				<p>'We have to pay in Pakistan I think that is why we get seen earlier but there is a waiting list all the time here (pg 1) Farhat</p> <p>'Now that I earn here I send money or my parents so they can get the best care they need (pg 30) Neelam</p> <p>'here we don't get a choice because the health service is free here, but over there we have to pay so the choice is yours' (pg 77) Hameeda</p> <p>'The NHS is free here... therefore we cannot choose who we see [elderly] beggars cant be choosers right' (pg 82) p1Ameena</p>
Theme Ten: Cultural difference				
	Sub theme: 10.4 have you experienced			
	Sub sub theme: 10.4.1 Towards your	Sub sub theme: 10.4.2	Sub sub theme: 10.4.3 Your beliefs and	

	racism	dress	Communication	practices
Summary	Participants felt they had mainly experienced verbally racial abuse.	Only one participant felt that people had stared at them because of their clothes.	Mainly participants could not speak English at all or only slightly.	Mainly participants did have never felt racial hatred towards them due to their beliefs and practice.
No of participants	Verbal: 4 participants stated people had said things to them and swore at them. Don't go out: 5 participants stated they did not go out. None: 5 participants stated they had never experienced any racism.	Stare: 1 participant stated people would stare at them. None: 11 participants stated they did not find people had a problem with their clothing. N/A: 2 participants did not comment.	Can't speak: 8 participants stated they could not speak English, and used family members if communication in English was a must. People don't have time: 2 participants felt that because they could not speak English people had no time for them. No problems: 5 participants stated they did not have a problem with communication.	None: 13 participants had not experienced racism due to their beliefs and practices. Everyone is the same: 1 participant felt that people thought every Muslim was the same.
Illustrative quotes	<p>'When I came first time people use to say things (pg 5) Farhat</p> <p>'People look at you funny, but if these lot where in our country then we would look at them like that (pg 19) Shagufta</p> <p>'It took me a long time to fit in here people see you are different (pg 30) Neelam</p> <p>'People look at you funny (pg 46) Tayiba</p> <p>'Who are these people to judge us' (pg 71) Roshin</p>	<p>"I have to admit my dress was looked upon as a problem" (pg 71) Roshin</p> <p>'I only wear Asian clothes on my days off they are just so comfortable (pg 80) Ameena</p>	<p>'People look at you funny because you cant speak English that is why no I take my daughters with me (pg 5) Farhat</p> <p>'I learnt English in India...If you cant speak like everyone else you don't fit in I found that (pg 30) Neelam</p> <p>'They think this lady cannot speak English we don't care what they say and just agree' (pg 65) Nazia</p> <p>'People are shocked when I open my mouth I have a Lancashire accent, its just funny seeing their faces (pg 83) Ameena</p> <p>"I cant speak English proper so people don't have time for you" (pg 85) Sofia</p>	<p>'People say we have too many children, but we do because at least on will look after you (pg 16) Shagufta</p> <p>'People think especially when I have been to the hospital that we are all the same (skin colour), but we are not we are all different how we live is different (pg 30) Neelam</p> <p>'I would not say anything about other people so they shouldn't about me (pg 46) Tayiba</p>

Theme Eleven: Health Practices				
	Sub theme: 11.1 Traditional practices	Sub theme: 11.2 Medical conventional practices	Sub theme: 11.3 Beliefs about ill health	Sub theme: 11.4 Exercising
Summary	All participants stated they pray	Participants all stated due to	Participants generally stated	Participants generally felt they
				Sub theme: 11.5 What health means to them
				Participants related healthy to their

	to Allah for better health.	their severity they would need to seek help from professional, although the majority of the participants stated they wanted only the operation.	good and bad are from Allah and we should learn to accept it.	did not have time for exercises due to their busy lifestyle. For participants who were given exercises by the physio the same applied they did not have time.	beliefs and practices. Participants generally felt being healthy was having the ability to pray and having faith.
<i>No of participants</i>	Pray: 14 participants stated the pray for better health. Peer Saab: 3 participants stated they get guidance from the peer Saab about ill health. Home remedies: 1 participant stated trying home remedies.	Want operation: 5 participants only wanted the operation and did not feel exercises or the medication helped at all. 1 participant did not want operation as she felt she was too old. Severity: 4 participants stated the severity of the condition pushed them to seek help. Pakistan: 1 participant stated she would go to Pakistan for treatment because she would get the choice whom to see. Would not go if male: 2 participants stated they would not seek help if only a male doctor was available.	Learn to accept: 9 participants stated Good, bad health is from Allah, and we should learn to accept it. Punishment: 2 participants felt they were being punished for some sins in the past. Cure: 1 participant stated God will send her a cure. Seek help: 2 participants stated if ill health is coming between you and Allah then you should seek help.	No time: 7 participants felt they had no time to complete any form of exercises. Cant: 3 participants stated because of ill health they could not do any exercises. Walk: 4 participants stated they walk everywhere and complete the exercise the physio had assigned to them.	Praying: 4 participants felt having the ability to pray meant being healthy to them. Faith: 2 participants felt having faith in Allah who will send you a cure were healthy. No medication: 4 participants stated being healthy to them meant not taking any medication at all. Active: 3 participants stated being active was being healthy. No time: 3 participants stated worrying about ill health was unhealthy. In addition, they had no time to be unhealthy due to their busy lifestyle.
<i>Illustrative quotes</i>	'I pray to God all the time to make be better (pg 5) Farhat 'We have a Peer Saab who visits at least twice a year, he guides us...Sometimes he tell us what to do, and gives us a taweez and things like that (pg 14) Naila 'The best form of treatment is praying and following the path of our prophet (pg 68) Roshin	'If a male doctor see me, it doesn't matter at all, he is helping me right...I should go to the doctors if this makes me better' (pg 39) Ghazala 'I don't want operation... is there any point to that, I am old now' (pg 44) Tayiba 'I will go and get treatment done in Pakistan' (pg 66) Nazia	'Allah states when you are ill, he will send you a cure (pg 6) Farhat 'Islam tells you to go to the doctors when you need help and to make sure you get better' (pg 12) Naila 'Good and bad are from Allah, but he also give you the knowledge to go out and find help (pg 29) Khalida 'The more you suffer the	'I do walk around here, but I don have time to do the exercise the physio told me (pg 27) Khalida 'I do pelvic floor exercise which are improving my problem (pg 82) Ameena 'I don't have time to do exercises really I do try and fit them in but sometimes it is hard (pg 87) Sofia	'Health is important, but I am so busy with the house and children I don't have time for myself (pg 12) Naila 'Not taking medication and not going to the doctors (pg 29) Khalida 'No nothing I have that many problems who cares one day I am going to die the sooner the better (pg 77) Hameeda 'active not having any health problems (pg 83) Ameena

		<p>'Would like someone to make me better' (pg 60) Nazia</p> <p>'I am waiting for operation now I have had the tablets and I sometimes use pads (pg 86) Sofia</p>	<p>more Allah purifies your soul (pg 30) Neelam</p> <p>'Islam also says if you are unable to pray because of a illness than you need to go to the doctors' (pg 77) Hameeda</p> <p>'Illness for me is like a punishment from Allah for something I have done wrong. I will only find a cure if God wishes me to (pg 87) Sofia</p>	
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Theme Twelve: Services Accessed

	Sub theme: 12.1 First port of call		Sub sub theme: 12.1.1 Communication	Sub sub theme: 12.1.2 Advice
Summary	All participants informed their GP's, when the problem become severe.		Participants stated their GP could speak Urdu so there was no problem telling them about UI.	All participants were referred to the hospital service, with information that UI is not normal, and help is available.
No of participants	GP: 14 participants informed their GP about UI.		Urdu: 12 participants stated they communicate in Urdu with their GP. English: 2 participants could speak English well. Take daughter in law: 1 participant took her daughter in law, although she could speak Urdu, she felt she ma miss information that her daughter in law was able to clarify.	Not normal: 12 participants were informed by their GP UI was not normal and help was available. UTL: 2 participants were informed that they are having recurrent UTI's and referred to hospital. Male: 1 participant was informed the consultant at the hospital may be male.
Illustrative quotes	'I told my GP (pg 88) Sofia		<p>'I told my GP I didn't have to take anyone with me because he speaks Urdu (pg 4) Farhat</p> <p>'take my daughter in law with me because sometimes I don't understand what they say' (pg 46) Tayiba</p>	<p>'Told me I will have to go to the hospital (pg 3) Farhat</p> <p>'It was happening more and more. Referred to physio (pg 15) Naila</p> <p>'Told me it is not normal... 'He [GP] told me the doctor in the hospital may be man ... but I have left all that behind because I need help' (pg 28) Khalida</p>

<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>
<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>
<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>
<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>	<p>1990-1991</p>

Theme twelve: Services Accessed				
	Sub theme: 12.2 Nurse specialist	Sub sub theme: 12.2.1 Management	Sub sub theme: 12.2.2 Satisfaction	Sub sub theme: 12.2.3 Restrictions
Summary	Mainly participants had seen the nurse specialist at the hospital.	Participants who had seen the nurse specialist had all had urodynamic tests, management strategies included medication, pads and a daily diary.	Generally, participants wanted an operation, and refused to take medication, without informing nurse specialist.	Restriction mainly included the inability to communicate directly with the nurse specialists.
No of participants	Seen: 11 participants had seen the nurse specialist. Not seen: 3 participants had not seen nurse specialist as yet.	Urodynamics: 11 participants had had urodynamics. Pads: 10 participants were given pads. Medication: 7 participants were taking medication. Self-catheterisation: 1 participant was taught self-catheterisation. Diary: 1 participant was advised to keep a diary of how many times she leaked urine in the day and the amount.	Refused to take medication: 4 refused to take medication. Wanted operation: 6 participants only wanted an operation. Pads: 2 participants were glad they got pads, as prior to seeing nurse specialist they pad for them. Not seen: 3 had not been seen by the nurse specialist. N/A: 6 participants did not comment.	Communication: 11 participants felt they had to rely on others as a means of communication.
Illustrative quotes	'I saw nurse and she did three tests on me (pg 4) Farhat 'Saw nurse 2 months ago (pg 23) Shahista 'Very nice lady (pg 36) Ghazala 'She was nice to me helped me a lot (pg 52) Nusrat	'started on tablets (pg 18) Shagufta "I take tablets too... 'I wear pad. I get them from Nurse (pg 24) Shahista 'If tablets don't work I can have a operation' (pg 40) Ghazala 'Tablets for UI ...but they don't help...nurse gave me pads too...'The nurse did a test and put water inside ... I have a diary too to write down how many times it happens....'I can have operation if it doesn't work' (pg 44) Tayiba 'She put water inside me to see how much came out when I coughed (pg 68) Roshin	'Nurse told me it was bad and I had to have a operation (pg 5) Farhat 'I am glad I got the pads because they really help...'I use to buy them before now I get them free (pg 27) Khalida Not taking medication for 10 days' making me feel ill (pg 36) Ghazala 'Nurse told me it was bad and I had to go to the doctors (pg 69) Roshin	'I have to take someone with me, because nurse is English (pg 5) Farhat 'I will not see a male, if I have to I will just live with my problem (pg 15) Naila 'take my daughter in law with me because sometimes I don't understand what they say' (pg 46) Tayiba 'I did not wear pads... because as Muslims we have to stay clean' (pg 52) Nusrat " '[tablets] don't work, it is still the same, they did tell me if this doesn't work than I will get a operation' (pg 75) Hameeda 'I haven't been taking them [tablets] for three days now... I don't think they do anything for me... 'Fed up of taking tablets' (pg 87) Sofia

Theme Twelve: Services Accessed				
	Sub theme: 12.3 Physiotherapist	Sub sub theme: 12.3.1 Management	Sub sub theme: 12.3.2 Satisfaction	Sub sub theme: 12.3.3 Restrictions
Summary	13 participants had accessed services through the physiotherapist.	All participants who had access this service were all given pelvic floor exercises.	Overall participants did not see any improvement in their health with the exercises, therefore were not satisfied with the service.	Participants generally stated they did not get time to complete the exercises as they had busy lifestyles.
No of participants	Yes: 13 participants had seen physio. Waiting appointment: 1 participant was waiting for her appointment.	Exercises: 13 participants were assigned exercises to complete.	No improvement: 9 participants did not feel any improvement in their UI. Hope: 3 participants hoped through the exercise their UI would get better.	No time: 12 participants stated they had not time to complete the exercises. No better: 9 participants stated they felt no better. Communication: 2 participants stated communication was the biggest problem for them.
Illustrative quotes	<p>“I have seen [physio] ... that was the first time I went to see someone” (pg 12) Naila</p> <p>“Referred by nurse. I have this problem because I have had seven children (pg 16) Shagufia</p> <p>“I was suppose to see Physio, waiting for letter” (pg 23) Shahista</p>	<p>“the lady physio showed me exercises” (pg3) Farhat</p> <p>“training days with physiotherapist” (pg 31) Neelam</p>	<p>“I just hope I get this problem sorted now that’s all” (pg 29) Khalida</p> <p>“I need help and they are providing the help” (pg 32) Neelam</p> <p>“I do exercises, I don’t have anything else to do” (pg 38) Ghazala</p> <p>“she is not doing anything for me, keeps saying do more exercises, but this is not helping... ‘told me because you have children, but I no children’ (pg 75) Nazia</p> <p>“its improved me (pg 81) Ameena</p>	<p>“I always take my daughters to the physio, when I see her... ‘I sometimes forget to do the exercises (pg 5) Farhat</p> <p>“They are not helping but I have to do them (pg 38) Ghazala</p> <p>“take my daughter in law with me because sometimes I don’t understand what they say” (pg 46) Tayiba</p>

Theme Twelve: Services Accessed				
	Sub theme: 12.4 Specialists	Sub sub theme: 12.4.1 Management	Sub sub theme: 12.4.2 Satisfaction	Sub sub theme: 12.4.3 Restrictions
Summary	Participants had seen a male consultant at RBH.	Participants that had seen consultant were informed about an operation. Out of these 4 participants wanted or had the operation.	Participants who had accessed this service were generally happy with their consultations.	Participants who accessed the service stated they had asked for a female doctor, but were not assigned to one.
No of participants	Sow consultant: 8 participants had seen a consultant for their UI. Not seen: 6 participants had not.	Awaiting operation: 1 participant had had the operation. Had operation: 3 participants had the	Operation: only one participant felt much better and health had improved. No improvement: 1 participant felt no	Female: 7 participants had requested a female doctor. Wrong: 2 participants stated they had done

		operation. Options explained: 8 participants who had seen the consultant stated their options were explained to them.	difference, but was informed could have a second operation if she lost weight. Waiting operation: 5 participants stated they were waiting for their operation, and hoped they would get better.	wrong by their religion seeing a male doctor. Communication: only one participant felt that things would be much better if she would have been able to communicate directly to the consultant herself.
<i>Illustrative quotes</i>		<p>'I had operation too... 'I can have another operation but doctor told me I need to loose weight (pg 5) Farhat</p> <p>'Mr Hill examined me... but it had to be done I needed help' (pg 69) Roshin</p> <p>'I can have an operation... 'I wear pads all the time... SH gave me tablets' (pg 87) Sofia</p>	<p>'Operation will make me better ... but it has not at all, it is still the same' (pg 4) Farhat</p> <p>'I just hope I get this problem sorted now that's all' (pg 29) Shahista</p> <p>'I am not happy with it has not made me better I still have the problem (pg 30) Khalida</p> <p>'Now when I pray namaz my water is not coming' (pg 53) Nusrat</p> <p>'I see Mr Hill soon and I know he will do his best to get me better again' (pg 70) Roshin</p> <p>'I think it would definitely be better if there was a lady doctor available it gives people that choice' (pg 83) Ameena</p>	<p>'I had to see a man (SH), I felt shy...as long as they do a good job... 'I asked the doctor for a female doctor' (pg 6) Farhat</p> <p>'If I have to go to see a man I wouldn't want any help at all' (pg 13) Naila</p> <p>'Would never let a male doctor examine her... 'Muslim woman should not expose her body to anyone (pg 49) Tayiba</p> <p>'I requested female doctor but I ended up with a man' (pg 59) Nusrat</p> <p>'I have told them I want to see a lady doctor, but they [professionals] say I will have to go Burnley, I am not going to Burnley' (pg 66) Nazia</p> <p>'I have no choice, I can leak everywhere or show a man... '[operation delayed] [by SH] wanted someone there who could speak Urdu and tell me things... 'I know I must be doing wrong seeing a male [SH]' (pg 87) Sofia</p>

				<p>...[24], [25], [26][27], [28], [29][30], [31], [32][33], [34], [35][36], [37], [38][39], [40], [41][42], [43], [44][45], [46], [47][48], [49], [50][51], [52], [53][54], [55], [56][57], [58], [59][60], [61], [62][63], [64], [65][66], [67], [68][69], [70], [71][72], [73], [74][75], [76], [77][78], [79], [80][81], [82], [83][84], [85], [86][87], [88], [89][90], [91], [92][93], [94], [95][96], [97], [98][99], [100], [101][102], [103], [104][105], [106], [107][108], [109], [110][111], [112], [113][114], [115], [116][117], [118], [119][120], [121], [122][123], [124], [125][126], [127], [128][129], [130], [131][132], [133], [134][135], [136], [137][138], [139], [140][141], [142], [143][144], [145], [146][147], [148], [149][150], [151], [152][153], [154], [155][156], [157], [158][159], [160], [161][162], [163], [164][165], [166], [167][168], [169], [170][171], [172], [173][174], [175], [176][177], [178], [179][180], [181], [182][183], [184], [185][186], [187], [188][189], [190], [191][192], [193], [194][195], [196], [197][198], [199], [200][201], [202], [203][204], [205], [206][207], [208], [209][210], [211], [212][213], [214], [215][216], [217], [218][219], [220], [221][222], [223], [224][225], [226], [227][228], [229], [230][231], [232], [233][234], [235], [236][237], [238], [239][240], [241], [242][243], [244], [245][246], [247], [248][249], [250], [251][252], [253], [254][255], [256], [257][258], [259], [260][261], [262], [263][264], [265], [266][267], [268], [269][270], [271], [272][273], [274], [275][276], [277], [278][279], [280], [281][282], [283], [284][285], [286], [287][288], [289], [290][291], [292], [293][294], [295], [296][297], [298], [299][300], [301], [302][303], [304], [305][306], [307], [308][309], [310], [311][312], [313], [314][315], [316], [317][318], [319], [320][321], [322], [323][324], [325], [326][327], [328], [329][330], [331], [332][333], [334], [335][336], [337], [338][339], [340], [341][342], [343], [344][345], [346], [347][348], [349], [350][351], [352], [353][354], [355], [356][357], [358], [359][360], [361], [362][363], [364], [365][366], [367], [368][369], [370], [371][372], [373], [374][375], [376], [377][378], [379], [380][381], [382], [383][384], [385], [386][387], [388], [389][390], [391], [392][393], [394], [395][396], [397], [398][399], [400], [401][402], [403], [404][405], [406], [407][408], [409], [410][411], [412], [413][414], [415], [416][417], [418], [419][420], [421], [422][423], [424], [425][426], [427], [428][429], [430], [431][432], [433], [434][435], [436], [437][438], [439], [440][441], [442], [443][444], [445], [446][447], [448], [449][450], [451], [452][453], [454], [455][456], [457], [458][459], [460], [461][462], [463], [464][465], [466], [467][468], [469], [470][471], [472], [473][474], [475], [476][477], [478], [479][480], [481], [482][483], [484], [485][486], [487], [488][489], [490], [491][492], [493], [494][495], [496], [497][498], [499], [500][501], [502], [503][504], [505], [506][507], [508], [509][510], [511], [512][513], [514], [515][516], [517], [518][519], [520], [521][522], [523], [524][525], [526], [527][528], [529], [530][531], [532], [533][534], [535], [536][537], [538], [539][540], [541], [542][543], [544], [545][546], [547], [548][549], [550], [551][552], [553], [554][555], [556], [557][558], [559], [560][561], [562], [563][564], [565], [566][567], [568], [569][570], [571], [572][573], [574], [575][576], [577], [578][579], [580], [581][582], [583], [584][585], [586], [587][588], [589], [590][591], [592], [593][594], [595], [596][597], [598], [599][600], [601], [602][603], [604], [605][606], [607], [608][609], [610], [611][612], [613], [614][615], [616], [617][618], [619], [620][621], [622], [623][624], [625], [626][627], [628], [629][630], [631], [632][633], [634], [635][636], [637], [638][639], [640], [641][642], [643], [644][645], [646], [647][648], [649], [650][651], [652], [653][654], [655], [656][657], [658], [659][660], [661], [662][663], [664], [665][666], [667], [668][669], [670], [671][672], [673], [674][675], [676], [677][678], [679], [680][681], [682], [683][684], [685], [686][687], [688], [689][690], [691], [692][693], [694], [695][696], [697], [698][699], [700], [701][702], [703], [704][705], [706], [707][708], [709], [710][711], [712], [713][714], [715], [716][717], [718], [719][720], [721], [722][723], [724], [725][726], [727], [728][729], [730], [731][732], [733], [734][735], [736], [737][738], [739], [740][741], [742], [743][744], [745], [746][747], [748], [749][750], [751], [752][753], [754], [755][756], [757], [758][759], [760], [761][762], [763], [764][765], [766], [767][768], [769], [770][771], [772], [773][774], [775], [776][777], [778], [779][780], [781], [782][783], [784], [785][786], [787], [788][789], [790], [791][792], [793], [794][795], [796], [797][798], [799], [800][801], [802], [803][804], [805], [806][807], [808], [809][810], [811], [812][813], [814], [815][816], [817], [818][819], [820], [821][822], [823], [824][825], [826], [827][828], [829], [830][831], [832], [833][834], [835], [836][837], [838], [839][840], [841], [842][843], [844], [845][846], [847], [848][849], [850], [851][852], [853], [854][855], [856], [857][858], [859], [860][861], [862], [863][864], [865], [866][867], [868], [869][870], [871], [872][873], [874], [875][876], [877], [878][879], [880], [881][882], [883], [884][885], [886], [887][888], [889], [890][891], [892], [893][894], [895], [896][897], [898], [899][900], [901], [902][903], [904], [905][906], [907], [908][909], [910], [911][912], [913], [914][915], [916], [917][918], [919], [920][921], [922], [923][924], [925], [926][927], [928], [929][930], [931], [932][933], [934], [935][936], [937], [938][939], [940], [941][942], [943], [944][945], [946], [947][948], [949], [950][951], [952], [953][954], [955], [956][957], [958], [959][960], [961], [962][963], [964], [965][966], [967], [968][969], [970], [971][972], [973], [974][975], [976], [977][978], [979], [980][981], [982], [983][984], [985], [986][987], [988], [989][990], [991], [992][993], [994], [995][996], [997], [998][999], [1000], [1001][1002], [1003], [1004][1005], [1006], [1007][1008], [1009], [1010][1011], [1012], [1013][1014], [1015], [1016][1017], [1018], [1019][1020], [1021], [1022][1023], [1024], [1025][1026], [1027], [1028][1029], [1030], [1031][1032], [1033], [1034][1035], [1036], [1037][1038], [1039], [1040][1041], [1042], [1043][1044], [1045], [1046][1047], [1048], [1049][1050], [1051], [1052][1053], [1054], [1055][1056], [1057], [1058][1059], [1060], [1061][1062], [1063], [1064][1065], [1066], [1067][1068], [1069], [1070][1071], [1072], [1073][1074], [1075], [1076][1077], [1078], [1079][1080], [1081], [1082][1083], [1084], [1085][1086], [1087], [1088][1089], [1090], [1091][1092], [1093], [1094][1095], [1096], [1097][1098], [1099], [1100][1101], [1102], [1103][1104], [1105], [1106][1107], [1108], [1109][1110], [1111], [1112][1113], [1114], [1115][1116], [1117], [1118][1119], [1120], [1121][1122], [1123], [1124][1125], [1126], [1127][1128], [1129], [1130][1131], [1132], [1133][1134], [1135], [1136][1137], [1138], [1139][1140], [1141], [1142][1143], [1144], [1145][1146], [1147], [1148][1149], [1150], [1151][1152], [1153], [1154][1155], [1156], [1157][1158], [1159], [1160][1161], [1162], [1163][1164], [1165], [1166][1167], [1168], [1169][1170], [1171], [1172][1173], [1174], [1175][1176], [1177], [1178][1179], [1180], [1181][1182], [1183], [1184][1185], [1186], [1187][1188], [1189], [1190][1191], [1192], [1193][1194], [1195], [1196][1197], [1198], [1199][1200], [1201], [1202][1203], [1204], [1205][1206], [1207], [1208][1209], [1210], [1211][1212], [1213], [1214][1215], [1216], [1217][1218], [1219], [1220][1221], [1222], [1223][1224], [1225], [1226][1227], [1228], [1229][1230], [1231], [1232][1233], [1234], [1235][1236], [1237], [1238][1239], [1240], [1241][1242], [1243], [1244][1245], [1246], [1247][1248], [1249], [1250][1251], [1252], [1253][1254], [1255], [1256][1257], [1258], [1259][1260], [1261], [1262][1263], [1264], [1265][1266], [1267], [1268][1269], [1270], [1271][1272], [1273], [1274][1275], [1276], [1277][1278], [1279], [1280][1281], [1282], [1283][1284], [1285], [1286][1287], [1288], [1289][1290], [1291], [1292][1293], [1294], [1295][1296], [1297], [1298][1299], [1300], [1301][1302], [1303], [1304][1305], [1306], [1307][1308], [1309], [1310][1311], [1312], [1313][1314], [1315], [1316][1317], [1318], [1319][1320], [1321], [1322][1323], [1324], [1325][1326], [1327], [1328][1329], [1330], [1331][1332], [1333], [1334][1335], [1336], [1337][1338], [1339], [1340][1341], [1342], [1343][1344], [1345], [1346][1347], [1348], [1349][1350], [1351], [1352][1353], [1354], [1355][1356], [1357], [1358][1359], [1360], [1361][1362], [1363], [1364][1365], [1366], [1367][1368], [1369], [1370][1371], [1372], [1373][1374], [1375], [1376][1377], [1378], [1379][1380], [1381], [1382][1383], [1384], [1385][1386], [1387], [1388][1389], [1390], [1391][1392], [1393], [1394][1395], [1396], [1397][1398], [1399], [1400][1401], [1402], [1403][1404], [1405], [1406][1407], [1408], [1409][1410], [1411], [1412][1413], [1414], [1415][1416], [1417], [1418][1419], [1420], [1421][1422], [1423], [1424][1425], [1426], [1427][1428], [1429], [1430][1431], [1432], [1433][1434], [1435], [1436][1437], [1438], [1439][1440], [1441], [1442][1443], [1444], [1445][1446], [1447], [1448][1449], [1450], [1451][1452], [1453], [1454][1455], [1456], [1457][1458], [1459], [1460][1461], [1462], [1463][1464], [1465], [1466][1467], [1468], [1469][1470], [1471], [1472][1473], [1474], [1475][1476], [1477], [1478][1479], [1480], [1481][1482], [1483], [1484][1485], [1486], [1487][1488], [1489], [1490][1491], [1492], [1493][1494], [1495], [1496][1497], [1498], [1499][1500], [1501], [1502][1503], [1504], [1505][1506], [1507], [1508][1509], [1510], [1511][1512], [1513], [1514][1515], [1516], [1517][1518], [1519], [1520][1521], [1522], [1523][1524], [1525], [1526][1527], [1528], [1529][1530], [1531], [1532][1533], [1534], [1535][1536], [1537], [1538][1539], [1540], [1541][1542], [1543], [1544][1545], [1546], [1547][1548], [1549], [1550][1551], [1552], [1553][1554], [1555], [1556][1557], [1558], [1559][1560], [1561], [1562][1563], [1564], [1565][1566], [1567], [1568][1569], [1570], [1571][1572], [1573], [1574][1575], [1576], [1577][1578], [1579], [1580][1581], [1582], [1583][1584], [1585], [1586][1587], [1588], [1589][1590], [1591], [1592][1593], [1594], [1595][1596], [1597], [1598][1599], [1600], [1601][1602], [1603], [1604][1605], [1606], [1607][1608], [1609], [1610][1611], [1612], [1613][1614], [1615], [1616][1617], [1618], [1619][1620], [1621], [1622][1623], [1624], [1625][1626], [1627], [1628][1629], [1630], [1631][1632], [1633], [1634][1635], [1636], [1637][1638], [1639], [1640][1641], [1642], [1643][1644], [1645], [1646][1647], [1648], [1649][1650], [1651], [1652][1653], [1654], [1655][1656], [1657], [1658][1659], [1660], [1661][1662], [1663], [1664][1665], [1666], [1667][1668], [1669], [1670][1671], [1672], [1673][1674], [1675], [1676][1677], [1678], [1679][1680], [1681], [1682][1683], [1684], [1685][1686], [1687], [1688][1689], [1690], [1691][1692], [1693], [1694][1695], [1696], [1697][1698], [1699], [1700][1701], [1702], [1703][1704], [1705], [1706][1707], [1708], [1709][1710], [1711], [1712][1713], [1714], [1715][1716], [1717], [1718][1719], [1720], [1721][1722], [1723], [1724][1725], [1726], [1727][1728], [1729], [1730][1731], [1732], [1733][1734], [1735], [1736][1737], [1738], [1739][1740], [1741], [1742][1743], [1744], [1745][1746], [1747], [1748][1749], [1750], [1751][1752], [1753], [1754][1755], [1756], [1757][1758], [1759], [1760][1761], [1762], [1763][1764], [</p>
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Appendix Twelve:

Initial coding/themes from the data

Appendix Twelve:

Initial coding/themes from the data

Appendix twelve: Initial coding/ themes from the data

Theme

1. General Knowledge about Urinary Incontinence

Sub theme

Definitions of UI

- P1: does not know
- P2: not having control over your urine
- P3: when you sneeze, laugh or cough and urine comes out
- P4: little bit of urine comes out
- P5: no control over bladder
- P6: not being able to control your bladder
- P7: when you cough or sneeze
- P8: leak water
- P9: don't know

Factors causing UI

- P1: don't know
- P2: childbirth
- P3: childbirth, old age
- P4: periods, flu/cold, childbirth, becoming loose
- P5: childbirth, illnesses i.e. stroke, old age
- P6: old age, childbirth
- P7: childbirth, periods
- P8: pregnancy, not sure
- P9: don't know

Strategies for dealing with UI

- P1: pads drink less, learnt to live with problem
- P2: change of clothing, pads, drinking less
- P3: drink less, exercises, stopping urine mid flow, pads
- P4: no don't know
- P5: drink less water
- P6: pelvic floor exercises, but did not keep them up
- P7: pelvic floor exercises, busy lifestyle to keep them up
- P8: drink less water and pelvic floor exercises
- P9: no idea

Theme

2. Impact of UI on daily life

Sub theme

Level of disruption caused to daily life

- P1: got use to it now, toilets self prior to activities; see it as a good aspect, God wanting her to pray all the time, negative what others may be thinking about her
- P2: wears pads all the time; very annoyed by it
- P3: annoys me, but have learnt to live with it

Theme

1. General Knowledge about Urinary Incontinence

Sub theme

Definitions of UI

P1: does not know

P2: not having control over your urine

P3: when you sneeze, laugh or cough and urine comes out

P4: little bit of urine comes out

P5: no control over bladder

P6: not being able to control your bladder

P7: when you cough or sneeze

P8: leak water

P9: don't know

Factors causing UI

P1: don't know

P2: childbirth

P3: childbirth, old age

P4: periods, flu/cold, childbirth, becoming fatter

P5: childbirth, illnesses i.e. stroke, old age

P6: old age, childbirth

P7: childbirth, periods

P8: pregnancy, not sure

P9: don't know

Strategies for dealing with UI

P1: pads drink less, learnt to live with problem

P2: change of clothing, pads, drinking less

P3: drink less, exercises, stopping urine mid-way, pads

P4: no don't know

P5: drink less water

P6: pelvic floor exercises, but did not learn them up

P7: pelvic floor exercises, busy lifestyle, not drinking

P8: drink less water and pelvic floor exercises

P9: no idea

Theme

2. Impact of UI on daily life

Sub theme

Level of disruption caused to daily life

P1: got used to it now, toilets full given it and now I get a good exercise

P2: wanting her to pray all the time, negative what others think about her

P3: about her

P4: were pads all the time, very annoyed

P5: annoys me, but have learnt to live with it

P4: affects me a lot, feeling horrible, dirty and smell
 P5: knocks my confidence, affects me a lot, wears small pads for protection all the time
 P6: varies, when I'm not well then its bad need to keep pads on all the time
 P7: quite bad, I have a very busy lifestyle, interferes with my daily life, I feel annoyed about it
 P8: affects me a lot I always wear pads
 P9: does not affect me now

Impact on quality of life

P1: no, see it as a blessing, because I pray most of the time
 P2: yes, always carry pads when out, if you look at it as a problem then it is
 P3: no, but its annoying
 P4: it is a problem, but not so big
 P5: aware where toilet is when out; very big problem
 P6: just a habit now, got used to it
 P7: unable to carry out daily tasks, without thinking
 P8: unable to go out with friends, needs to know where it is
 P9: no, it's my own fault, does not affect me

Theme

3. Influences of Religion and Culture on the behaviour relating to UI

Sub theme

Culture

3.1.1. Definitions of Culture

P1: society
 P2: influences of society, what others accept from you?
 P3: what people tell you i.e. mother, grandparents etc
 P4: what people tell you?
 P5: the way people are brought up, influences on others (community)
 P6: traditions that have been passed down
 P7: influences of society
 P8: what others say?
 P9: community we live in

3.1.2. Influences of Culture on behaviour

P1: what should it matter what others think
 P2: strong influence, but gone against it for my own good
 P3: does influence me, but never stopped me
 P4: doesn't stop me, doesn't matter what others think
 P5: culture is as important as religion
 P6: culture has never stopped me, not important what others think
 P7: culture as important as religion
 P8: culture as important as religion
 P9: not important, doesn't matter what others think

Religion

3.2.1. Definitions of Religion

3.2.1. Beliefs of Religion

Religion

- P1: what should I matter what others think
- P2: strong influence, but gone against it for my own good
- P3: does influence me, but never stopped me
- P4: doesn't affect me, doesn't matter what others think
- P5: culture is as important as religion
- P6: culture has never stopped me, not important what others think
- P7: culture as important as religion
- P8: culture as important as religion
- P9: not important, doesn't matter what others think

3.1.2. Influence of Culture on behavior

- P1: community we live in
- P2: what others say?
- P3: influence of society
- P4: traditions that have been passed down
- P5: the way people are brought up, influence on others (community)
- P6: what people tell you?
- P7: what people tell you I.e. mother, grandparents etc
- P8: influence of society, what others expect from you?
- P9: society

3.1.1. Definition of Culture

Sub theme
Culture

3. Influence of Religion and Culture on the behaviour related to life

Theme

- P1: no, not as a blessing, because I pray most of the time
- P2: yes, always carry pads when out, if you look at it as a problem then it is
- P3: no, but it's annoying
- P4: it is a problem, but not a big
- P5: aware where toilet is when out; very big problem
- P6: just a habit now, got used to it
- P7: unable to carry out daily tasks, without thinking
- P8: unable to go out with friends, needs to know where it is
- P9: no, it's my own fault, does not affect me
- P1: no, it's my own fault, does not affect me
- P2: aware where toilet is when out; very big problem
- P3: just a habit now, got used to it
- P4: unable to carry out daily tasks, without thinking
- P5: unable to go out with friends, needs to know where it is
- P6: just a habit now, got used to it
- P7: yes, always carry pads when out, if you look at it as a problem then it is
- P8: no, not as a blessing, because I pray most of the time
- P9: impact on quality of life
- P1: does not affect me now
- P2: affects me a lot I always wear pads
- P3: annoyed about it
- P4: quite bad, I have a very busy lifestyle, interfere with my daily life, I feel
- P5: varies, when I'm not well then the need to keep pads on all the time
- P6: affects me a lot, feeling horrible, dirty and small
- P7: knows my confidence, affects me a lot, wears small pads for protection
- P8: affects me a lot, feeling horrible, dirty and small

P1: Islam
 P2: What is written in Quran?
 P3: set of rules for people to abide by for the living of their daily lives
 P4: Islam
 P5: Islam: what is written?
 P6: Islam: what is written?
 P7: what is written?
 P8: Islam
 P9: religion is religion

3.2.2. Influences of Religion on behaviour

P1: everything I do is what is written in Islam
 P2: its important of course, but I went against it for contraception use
 P3: very important, teaches you how to live
 P4: I always question whether I can do something by religion and I Always ask my husband
 P5: try to follow religion as much as possible
 P6: try and live my life the way it is written
 P7: religion and culture play an equal part without culture we don't follow religion correctly
 P8: live the way is written, influences me a lot
 P9: very important, if religion says no then its no; but I would always ask my husbands permission

Theme

4. Contact with health services

Sub theme

4.1 *Experiences of accessing health services*

4.1.1. factors affecting decision to seek help from health professionals

P1: ill health, depending on whether my daughters available to take me
 P2: gender of doctor; parents influence
 P3: severity of problem, depending on what problem I have and the sex of the doctor
 P4: severity of problem
 P5: gender of doctor; society
 P6: severity of problem
 P7: sex of GP; family; husband; it would stop me if the doctor was Asian
 P8: language barrier; severity of problem
 P9: me myself; I decide

4.1.2. Factors influencing disclosure and discussion of UI with health professionals

P1: communication language barrier
 P2: gender; embarrassment; fear of examination
 P3: embarrassment; admitting I had a problem; examination
 P4: depending how bad problem was; embarrassing; shy
 P5: severity
 P6: severity; how much it affected me
 P7: embarrassment; feeling uncomfortable

- P1: Islam
P2: What is written in Quran?
P3: set of rules for people to abide by for the living of their daily lives
P4: Islam
P5: Islam: what is written?
P6: Islam: what is written?
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3.2.2. Influence of Religion on behaviour

- P1: everything I do is what is written in Islam
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P5: try to follow religion as much as possible
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P2: gender; embarrassment; fear of examination
P3: embarrassment; admitting I had a problem; examination
P4: depending how bad problem was; embarrassing; shy
P5: severity
P6: severity; how much it affected me
P7: embarrassment; feeling uncomfortable

P8: severity; language

P9: husband' permission; gender of doctor; embarrassment

Practice Nurse

P1: communication; cannot speak English

P2: embarrassing; depending on severity

P3: no problem; nurse is female

P4: no problem nurse is female

P5: would not go to nurse either; feel like the nurse is judging me because I am Asian; looks at me like I can't speak English, until I open my mouth to speak

P6: no problem would tell her

P7: would feel more comfortable would discuss because she is a female

P8: wouldn't be able to because I can't that well English

P9: no problem, would tell her

GPs

P1: I would tell my GP he is male but I am able to communicate with him although it's embarrassing

P2: no cause he is male, wouldn't want him to examine me

P3: no cause he's male; would not discuss with any male

P4: embarrassing would not tell a man

P5: no he is male

P6: no problem I would tell him able to communicate well

P7: no doctor is male husband wouldn't approve, embarrassing

P8: depends on how severe it is; no problem speaking to GP he is male but I am able to speak in my own language

P9: language barrier would not know how to tell him, embarrassing

4.1.3. Factors influencing the decision-making process

P1: how bad problem is

P2: state of health; severity of problem

P3: family/husband; severity of problem

P4: decide myself; depending on what the problem is

P5: husband, parents

P6: severity of problem, inform husband first, ability to communicate

P7: society, worry what others think, parents, husband

P8: society, language, children's problems; increased pain; illness

P9: decide by myself, ability to speak English

4.1.4. Perceptions of the effectiveness of written documentation

P1: leaflets in Urdu too hard to understand written in pure Urdu

P2: written in pure Urdu, plus not widely available for the percentage of population

P3: cannot read Urdu

P4: good for people who can't read English; easy to understand, very effective

P5: not available widely, vague, inappropriate wording

P6: unable to read Urdu

P7: reasonable wording, good for people who cannot read English

P8: quite good, very effective, easy to read

P9: very helpful, wording fine

- P1: letters in Urdu too hard to understand written in pure Urdu
 P2: written in pure Urdu, plus not widely available for the percentage of population
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 P7: reasonable wording, good for people who cannot read English
 P8: quite good, very effective, easy to read
 P9: very helpful, wording fine

4.1.4. Perceptions of the effectiveness of written communication

- P1: decide by myself, ability to speak English
 P2: society, language, children's problems; increased pain, illness
 P3: society, worry what others think, parents, husband
 P4: severity of problem, inform husband first, ability to communicate
 P5: husband, parents
 P6: decide myself; depending on what the problem is
 P7: family/husband; severity of problem
 P8: state of health; severity of problem
 P9: how bad problem is

4.1.3. Factors influencing the decision-making process

- P1: language barrier would not know how to tell him, embarrassing
 but I am able to speak in my own language
 P2: depends on how severe it is; no problem speaking to GP, he is male
 P3: no doctor is male husband wouldn't approve, embarrassing
 P4: no problem I would tell him able to communicate well
 P5: no he is male
 P6: embarrassing would not tell a man
 P7: no cause he's male; would not discuss with any male
 P8: no cause he is male, wouldn't want him to examine me
 although it's embarrassing
 P9: I would tell my GP he is male but I am able to communicate with him

GPs

- P1: no problem, would tell her
 P2: wouldn't be able to because I can't that well English
 P3: would feel more comfortable would discuss because she is a female
 P4: no problem would tell her
 P5: would not go to nurse either; feel like the nurse is judging me
 P6: no problem nurse is female
 P7: no problem; nurse is female
 P8: embarrassing; depending on severity
 P9: communication; cannot speak English

Practice Nurse

- P1: husband's permission; gender of doctor; embarrassment
 P2: severity; language

Appendix Thirteen:

Extracts from the field notes

Appendix Thirteen: Extracts from the field notes

Appendix thirteen: extracts from the field notes

20th November 2006

10.00: First interview: I am sat outside in my car now waiting to go in to see my first participant. Remember no interruptions and talk about myself first. Ok cool I am nervous hope this goes ok.

I have worn my Asian clothes today and have a scarf on as this lady is elderly; 70 years old mum said I should wear these clothes. Feel a bit awkward but oh well just get in.

1210: interview has completed and I am sat in my car. I think it went well, I did not interrupt and I let X talk. What a nice lady, she reminds me of gran. X talked to me in Urdu, and I did respond back in Urdu, she kept saying I understand what you mean your Urdu is fine. Yeah now that is not true, but the encouragement was nice.

X and I sat in room downstairs which was her bedroom. One end of the room she had a bed and a commode. This room was always locked and she kept hold of the key. The room was very dark and cold. Everything appeared to be locked with a padlock and key. I removed my shoes as I entered the hallway and waited to be asked to sit down.

X was alone at home at the time of interview; she had just finished cooking, and was waiting for me. X had printed off a list of her medication for me and handed it over prior to interviewing. X was aware that I was a nurse, and would help her with why she may be on certain medication. Looking at the list I could not even tell her why she may have been on such medication.

Throughout the interview X asked repeatedly if I would like any food or drinks. I didn't want any but hoped this would not offend her. X talked freely to me about her time in the UK, what barriers she had faced and her life in general.

I had achieved what I intended to in this interview, let's hope they all goes as well as this.

27th November 2006

11.30: Eleventh interview: today is the eleventh; things appear to be going fine. The lady I am interviewing today is a 69 year old Pakistani woman, who I have cared for as a nurse on SAU, who had multiple admissions for various problems. Hopefully this interview will go well.

14.10: Just got out this interview, oh my god this must have been one of the worse interviews. I did not interview X at all it felt as if she was interviewing me throughout. As I walked in the house, I knew that I had to remove my shoes and wait to be seated. My first impression about the house was 'it smells' yep of curry, it was very strong. X walked in and sat what looked like a thrown, on all the four walls there were pictures and verses of the Quran.

I began with telling X about the project and who I was. X interrupted me abruptly and asked whether I was a Muslim, to which I did respond by saying 'yes'. X continued with the question by asking whether my parents were Indian or Pakistani. I told her my parents originated from India, to which she responded by telling me that Indian's are not real Muslims. I had heard this comment throughout my life.

Although I was offended by this comment I decided to leave it and carry on. Again I was interrupted and was asked why I worked and why I dress in western clothes and why have my parents not stopped me from living my life the way I was ... I didn't understand what she meant by this and I didn't ask either. X reminded me of a head teacher, you do not question someone that bought out this child in me that I had become frightened.

26th November 2008

14:00: First interview. I am sat outside in my car now waiting to go in to see my first participant. Remainder no interruptions and talk about myself first. OK cool. I am nervous hope this goes ok.

I have worn my Asian clothes today and have a scarf on as this lady is elderly. 70 years old mum said I should wear these clothes. Feel a bit awkward but oh well just get in.

12:10: Interview has completed and I am seen my car. I think it went well. I did not interrupt and I let X talk. What a nice lady, she reminds me of gran. X talked to me in Urdu, and I did respond back in Urdu, she kept saying I understand what you mean your Urdu is fine. Yeah now that is not true, but the encouragement was nice.

X and I sat in room downstairs which was her bedroom. One end of the room she had a bed and a commode. This room was always locked and she kept hold of the key. The room was very dark and cold. Everything appeared to be locked with a padlock and key. I removed my shoes as I entered the hallway and waited to be asked to sit down.

X was alone at home at the time of interview, she had just finished cooking, and was waiting for me. X had printed off a list of her medication for me and handed it over prior to interviewing. X was aware that I was a nurse, and would help her with why she may be on certain medication. Looking at the list I could not even tell her why she may have been on such medication.

Throughout the interview X asked repeatedly if I would like any food or drink. I didn't want any but hoped this would not offend her. X talked freely to me about her time in the UK, what barriers she had faced and her life in general.

I had achieved what I intended to in this interview, let's hope they all goes as well as this.

27th November 2008

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14:10: Just got out of this interview, oh my god this must have been one of the worse interviews. I did not interview X at all it felt as if she was interviewing me throughout. As I walked in the house, I knew that I had to remove my shoes and wait to be seated. My first impression about the house was 'it smells' yep of curry, it was very strong. X walked in and sat what looked like a throne, on all the four walls there were pictures and verses of the Quran.

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Although I was offended by this comment I decided to leave it and carry on. Again I was interrupted and was asked why I worked and why I dress in western clothes and why have my parents not stopped me from living my life the way I was ... I didn't understand what she meant by this and I didn't ask either. X reminded me of a head teacher, you do not question someone that brought out this child in me that I had become frightened.

X called out to her daughters and daughter-in-laws, and much to my surprise all six girls were wearing the hijab and niqaab in the house, there was clearly no males around, so why had they worn this? X pointed to all six and informed me that I should dress like this (I was wearing my uniform). As I looked over at the women I noticed one thing, that all had their heads down and did not once look up.

X asked one of the women to bring me some tea, which I don't drink but because I didn't want to be told off for something else I drunk it.

The whole interview took place this way; I was not able to ask even one question about the study. X would interrupt and question me and my upbringing. Two hours and not asked one question I realised it must be time to give up.

I am now sat in the car in my own safety and just thinking did I really go through all that. I have a supervisory meeting tomorrow; maybe I should bring this up.

12th November 2007

17:30: I remember meeting this girl at the information session headed by a physiotherapist at RBH. She appeared very quiet then. Let's hope this interview is not quiet.

20:10: I am home now. God that was one interview. I actually feel really sorry for that woman. As I walked in X gave me a hug, which to me was weird. X's four children were in the house at the time of interview.

The interior appeared very modern and minimal; a couple of religious frames and that was it. I was quite surprised by this as X originates from Pakistan, although her husband was born and brought up in the UK.

I was dressed in my uniform and took my shoes off on entering the house although X informed me not to bother, but I had already done. I waited till X asked me to sit down.

X started the interview herself and told me about her life in Pakistan, but kept stopping and stating I wouldn't understand as I was born in the UK. X began to cry, and for a second I thought I had offended her with some comment I had made. No I had not even spoke X was doing all the talking. X disclosed some personal information to me regarding her relationship with her husband. I could not say I understand but I knew that arranged marriages especially when both are from different countries, there will always be problems, and this was through my own experience.

On many occasions I asked X that maybe we should not carry on with the interview but X requested that she would like to. I remember thinking at this stage, is this lady lonely, what kind of a life she may have if she was still in Pakistan. It must be horrible for her.

Throughout talking to X her children who probably age wise were six, five, four and two, would run around and sit on my lap. How do you tell someone you don't like children? The four year old boy asked me to feed him, so whilst interviewing X I was feeding a child. If my mum saw this she would be in shock.

As the interview came to an end, X asked whether she would be able to contact me just to talk, as she felt that she had made a friend. For some reason I could not say no, and actually felt really sorry for her.

As I got up to leave I remember her husband walking into the house. He appeared to be decent, but I couldn't help but think how he could treat someone the way he is.

19th November 2007

0930: I am sat outside X house, waiting to go in for the interview. When I dropped the information pack off a couple of days ago, X daughter in law opened the door. I

X called out to her daughter and daughter-in-laws, and went to my room as the girls were wearing the hijab and nippah in the house, there were clearly no males around, so why had they worn this? X pointed to all six and informed me that a shroud dress like this (I was wearing my uniform). As I looked over at the women I noticed one thing that all had their heads down and did not once look up. X asked one of the women to bring me some tea, which I don't think but because I didn't want to be told off for something else I drank it. The whole interview took place this way; I was not able to ask even one question about the study. X would interrupt and question me and my questioning. Two hours and not asked one question I realised it must be time to give up. I am now sat in the car in my own safety and just thinking did I really go through all that I have a supervisory meeting tomorrow; maybe I should bring this up.

12th November 2007

13:30: I remember meeting this girl at the information session headed by a psychiatrist at RBH. She appeared very quiet then. Left home this interview is not quiet. 20:10: I am home now. God that was one interview. I actually feel really sorry for that woman. As I walked in X gave me a hug, which to me was weird. X a four children were in the house at the time of interview. The interior appeared very modern and minimal; a couple of religious items and that was it. I was quite surprised by this as X originates from Pakistan, although her husband was born and brought up in the UK. I was dressed in my uniform and took my shoes off on entering the house although X informed me not to bother, but I had already done. I waited till X asked me to sit down.

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On many occasions I asked X that maybe we should not carry on with the interview but X requested that she would like to. I remember thinking at this stage is this really lonely, what kind of a life she may have if she was still in Pakistan. (I must be terrible terrible).

Throughout talking to X her children who probably age wise were six, five, four and two, would run around and sit on my lap. How do you tell someone you don't like children? The four year old boy asked me to feed him, so what interviewing X was feeding a child. If my mum saw this she would be in shock. As the interview came to an end, X asked whether she would be able to contact me just to talk, as she felt that she had made a friend. For some reason I could not say no and actually felt really sorry for her.

As I got up to leave I remember her husband walking into the house. He appeared to be decent, but I couldn't help but think how he could treat someone the way he is.

19th November 2007

09:30: I am sat outside X house, waiting to go in for the interview. When I checked the information pack off a couple of days ago, X daughter in law opened the door.

remember this girl from mosque, she has changed so much. I hope she is not going to sit in the interview.

11:50: just got out the house. I hope I never have to see this family again. X daughter in law the one I knew was not there, thank god. But her youngest daughter in law was there, which was not a problem, actually it was a god send to be honest.

I walked in, took my shoes off and waited to be seated. X was in a bed that was placed in the living room. I think this is where she stays, as around her she had a commode, medication in a large container, and some religious books.

X daughter in law informed her that the 'nurse' was here; X sat up in her bed. I was instructed to sit on the bed. The environment was strange, clearly where X stayed most of the day, (in her bed) was also the living room for the whole family. The television and the dining table were also in this room. For some reason I found this strange as X's commode was in the same room.

Before I began, I asked the daughter in law if her husband, X's son would be staying in this same room as her was sat there waiting for me to begin. I told the daughter in law that I would be discussing urinary incontinence a problem that his mother has. He left the room.

This was a difficult interview; X was hard of hearing and would talk very loud, in Punjabi which I do not understand at all. X's daughter in law told her to speak softly on numerous occasions; I think she must have seen my face. I was so glad the daughter in law was present as x would speak to her in Punjabi and then translator to me in English. I had offered X the interpreter but she had refused, well her daughter in-law had.

X had informed me hat she was going to Hajj in the next two weeks, but had difficulty mobilising herself, for which she has been given a wheelchair for. Although it is too small and she does not fit in it. X and her daughter in law asked me to contact the suppliers and get the chair changed; I told them that was not what I could do as this was outside my specialist. X told me that as a Muslim I have a duty to help other Muslims, and if I didn't then I would get cursed by God. WHAT?!! I have never heard such a thing! So guess what I did contact the company in front of the two ladies, and organised a date for the suppliers to come to the house before she left for Mecca in two weeks time.

This was the first thing that happened. Throughout the interview I realised that X had not been taking her medication that had been prescribed by the nurse specialist for her incontinence problems. Which X had not been taking, as they made her feel nauseous? I told X to contact the nurse, to which I was told that is what I should do for her, yeah once again as a Muslim this was my role.

I have never felt so 'crap' about myself as I have done today interviewing. I have another interview to complete today; god knows what's going to happen then.

I did contact the nurse specialist regarding the medication issues, as X's daughter in law contacted me again as they had my number on the information pack, they also rung me to ask to contact the suppliers of the wheelchairs to see when they would be visiting.

14th December 2007

14:00: today I am interviewing my final lady, another Pakistani lady. I have really had enough of these women telling me that I am not a true Muslim and finding fault in everything about me. Suppose dad always says just listen with one ear if its useful maintain it, or just let it be. People will always talk.

Fingers crossed and here we go.

15:10: Done!! Interview much to my surprise went really well. X was a lovely lady.

remember this girl from inside, and I was not in the room at the time, I was not in the room at the time, I was not in the room at the time.

I just got out the house, I don't know where I went, I don't know where I went, I don't know where I went.

In law the only I know was not there, I don't know where I went, I don't know where I went, I don't know where I went.

was there, which was not a picture, I don't know where I went, I don't know where I went, I don't know where I went.

I walked in, took my shoes off, and I don't know where I went, I don't know where I went, I don't know where I went.

placed in the living room, I don't know where I went, I don't know where I went, I don't know where I went.

concord, medication is a hard one, I don't know where I went, I don't know where I went, I don't know where I went.

X daughter in law informed me that I don't know where I went, I don't know where I went, I don't know where I went.

instructed to all on the day, I don't know where I went, I don't know where I went, I don't know where I went.

most of the day, I don't know where I went, I don't know where I went, I don't know where I went.

television and the drug store, I don't know where I went, I don't know where I went, I don't know where I went.

strange as X's command was to me, I don't know where I went, I don't know where I went, I don't know where I went.

Before I began, I asked the daughter in law, I don't know where I went, I don't know where I went, I don't know where I went.

in this same room as far as I know, I don't know where I went, I don't know where I went, I don't know where I went.

law that I would be discussing, I don't know where I went, I don't know where I went, I don't know where I went.

He left the room.

This was a difficult interview, I don't know where I went, I don't know where I went, I don't know where I went.

Purged which I do not understand, I don't know where I went, I don't know where I went, I don't know where I went.

on numerous occasions, I don't know where I went, I don't know where I went, I don't know where I went.

daughter in law was present as X was in the room, I don't know where I went, I don't know where I went, I don't know where I went.

me in English, I don't know where I went, I don't know where I went, I don't know where I went.

in-law had.

X had informed me that she was going to, I don't know where I went, I don't know where I went, I don't know where I went.

implied herself, for whom she was going, I don't know where I went, I don't know where I went, I don't know where I went.

enough and she does not, I don't know where I went, I don't know where I went, I don't know where I went.

enough and get the chair changed, I don't know where I went, I don't know where I went, I don't know where I went.

was outside my apartment, I don't know where I went, I don't know where I went, I don't know where I went.

Mother, and if I didn't, I don't know where I went, I don't know where I went, I don't know where I went.

such a thing, I don't know where I went, I don't know where I went, I don't know where I went.

ordered a date for the subject, I don't know where I went, I don't know where I went, I don't know where I went.

two weeks time.

This was the first thing that happened, I don't know where I went, I don't know where I went, I don't know where I went.

not been taking her medication, I don't know where I went, I don't know where I went, I don't know where I went.

her incontinence problem, I don't know where I went, I don't know where I went, I don't know where I went.

nauseous, I don't know where I went, I don't know where I went, I don't know where I went.

former, years ago, I don't know where I went, I don't know where I went, I don't know where I went.

I have never felt so good, I don't know where I went, I don't know where I went, I don't know where I went.

another interview to complete today, I don't know where I went, I don't know where I went, I don't know where I went.

I did contact the nurse specialist, I don't know where I went, I don't know where I went, I don't know where I went.

law contacted me again, I don't know where I went, I don't know where I went, I don't know where I went.

ing me to ask to contact the subject, I don't know where I went, I don't know where I went, I don't know where I went.

visiting.

14th December 2007

14:00 today I am interviewing my wife, I don't know where I went, I don't know where I went, I don't know where I went.

enough of these women, I don't know where I went, I don't know where I went, I don't know where I went.

everything about me, I don't know where I went, I don't know where I went, I don't know where I went.

maintain it, I don't know where I went, I don't know where I went, I don't know where I went.

Fingers crossed and here we go.

18:00 Donnell interview, I don't know where I went, I don't know where I went, I don't know where I went.

I was in the room, I don't know where I went, I don't know where I went, I don't know where I went.

As I knocked on the door a man opened it, and told me to come in, spoke English good sign. I waited in the hallway and removed my shoes. X walked up to me and told me to sit in the 'front room'. This room was clearly where X and the family would pray. There was Quranic verses in frames and religious books.

X would speak in English and Urdu, she is Pakistani lady. X husband walked in the room with tea and biscuits and then left me and X to talk. X had two children who did not at all interrupt us, wow that is a surprise.

X was aware that I was a nurse as I wore my uniform for the interview. X had informed me that due to her inability to communicate directly in English with the consultant her surgery had to be delayed, X requested that I attend her next consultation with her and help with the communication process. This appointment was in two days, I didn't want to get involved in this. Although I informed X that when it came nearer the time if she contacted me I would attend.

I had to say this I didn't want another lady to curse me.

I discussed my concerns to the supervisory team who informed me that I should clearly tell these women what my role is. But do they understand that for these women I was a nurse and most importantly a Muslim woman that would or should or had the duty in their eyes to help them in all their problems.

As I knocked on the door a man opened it, and told me to come in, spoke English good sign. I waited in the hallway and removed my shoes. X walked up to me and told me to sit in the front room. This room was clearly where X and the family would pray. There was Quranic verses in frames and religious books. X would speak in English and Urdu, she is Pakistani lady. X husband walked in the room with her and biscuits and then left me and X to talk. X had two children who did not at all interfere us, now that is a surprise. X was aware that I was a nurse as I wore my uniform for the interview. X had informed me that due to her inability to communicate directly in English with the consultant her surgery had to be delayed. X requested that I attend her next consultation with her and help with the communication process. This appointment was in two days, I didn't want to get involved in this. Although I informed X that when it came nearer the time I would attend. I had to say this I didn't want another lady to chase me.

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Appendix Fourteen:

Publication(s)

Appendix F

Publication

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1. Sange, C; Thomas, L; Lyons, C; Hill, S; (2008) Urinary Incontinence in Muslim Women. *Nursing times*. Vol 104 (issue 25) pp 49-52 (Published article).
2. Sange, C., Downe, S., Thomas, G., Hill, S., (In press) The meaning of urinary incontinence from a Muslim woman's point of view. (In press).

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2. Sange, C.; Dowe, S.; Thomas, G.; Hill, S. (in press) The meaning of urinary incontinence from a Muslim women's point of view. (in press).

Urinary Incontinence in Muslim women

AUTHORS Chandbi Sange, BSc, RGN, is PhD student; Dr Lois Thomas, PhD, BA, RGN, is senior research fellow; Dr Christina Lyons, PhD, MSc, RNT, DPSN, RMN, Teacher Certificate, is senior research fellow; all at University of Central Lancashire. Mr Simon Hill, MB, BS, MRCOG, is consultant gynaecologist, East Lancashire Hospitals NHS Trust.

ABSTRACT Sange, C. et al (2008) Urinary incontinence in Muslim women. *Nursing Times*; 104, 25, 49–52.

This article describes the results of a qualitative study that explores how religion and culture influence Muslim women's decisions to seek healthcare for urinary incontinence.

Urinary incontinence (UI) has a much more devastating effect on the quality of life of Muslim women than on those who are Jewish, Hindu or Christian (Chaliha and Stanton, 1999). For Muslim women, praying is seen as a relationship between the person and God (Naqib al-Misri and Keller, 1994) – leaking urine is a barrier.

Ablution (wadu) is a cleansing ritual carried out by every Muslim prior to prayers. The passing of stool, flatus or urine while under ablution necessitates carrying out the ritual again as cleanliness during prayers is required (Naqib al-Misri and Keller, 1994). Prayers (namaz), performed five times a day at different intervals, require a Muslim to stand, bend and sit while reciting the verses of the Quran (Islamic Vision, 1989). These actions can cause a leakage for a person who is incontinent. This process of leaking urine and cleansing can have a negative effect on the individual's psychological health, as it brings with it associations of guilt and punishment. Religious beliefs may also create a sense of fatalism, as a person may not feel it is worth seeking treatment as they think their illness is not in their sphere of control but rely on supernatural beliefs and powers (Kelleher et al, 1994).

It is crucial for Muslim women with UI to ask for help to enable them to carry out their daily religious duties (Walsh, 1998). Previous research has found the more severe a leakage, the greater the distress and the more restricted activities become, which is reflected in studies conducted in various ethnic groups (Heit et al, 2006; Samuelsson et al, 1997; Lagro-Janssen et al, 1992; Herzog et al, 1988; Yarnell and Leger, 1979). In these circumstances, people are more likely to consider seeking help (Samuelson et al, 1997; Burgio et al, 1994; Burgio, 1991; Ouslander and Abelson, 1990).

Information gained from an urogynaecologist at a local NHS trust suggested a low percentage of Muslim women accessed services for UI. This may be due to a lack of knowledge about the condition or the sensitive nature of the subject. For example, Wilkinson (2001) found Asian women felt that health professionals were not interested in their problems and did not provide adequate support.

An inability to understand or fully understand spoken English can also make individuals reluctant to seek help (Hagggar, 1994; Bhopal, 1986; Anderson, 1985), and communication barriers can play a role in non-compliance to treatment (Tufnell et al, 1994; McAvory and Sayeed, 1989). Relatives are often used as interpreters in consultations – this can lead to personal details that the patient may not be willing to share being disclosed to other family members, or misinterpretation in medical consultations, which can lead to potential clinical mismanagement. It may not be possible to translate clinical and medical terminology accurately to a target language (Wilkinson and Williamson, 1995).

The health-information needs of people from minority ethnic groups differ due to different cultural beliefs and values and their effects of those on healthcare practices (Rashidi and Rajaram, 2000; Ashing-Giwa and Ganz, 1997). An understanding of how cultural and religious beliefs influence and inform women's decisions in relation to UI is required to help health professionals provide a culturally sensitive service,

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Urinary incontinence (UI) has a much more devastating effect on the quality of life of Muslim women than on those who are Jewish, Hindu or Christian (Challis and Stanton, 1999). For Muslim women, praying is seen as a relationship between the person and God (Fajali al-Mish and Keller, 1994) - leaving urine is a taboo.

Adhoun (wudu) is a cleansing ritual carried out by every Muslim prior to prayer. The passing of stool, flatus or urine while under adhoun necessitates carrying out the ritual again as cleanliness during prayer is required (Fajali al-Mish and Keller, 1994). Prayers (Namaz), performed five times a day at different intervals, require a Muslim to stand, bend and sit while reciting the verses of the Quran (Islamic Vision, 1999). These actions can cause a leakage for a person who is incontinent. The process of leaving urine and cleaning can have a negative effect on the individual's psychological health, as it brings with it associations of guilt and punishment. Religious beliefs may also create a sense of fatalism as a person may not feel it is worth seeking treatment as they think their illness is not in their sphere of control but rely on supernatural beliefs and powers (Kellerton et al, 1994).

It is crucial for Muslim women with UI to ask for help to enable them to carry out their daily religious duties (Waleis, 1999). Previous research has found the more severe a leakage, the greater the distress and the more restricted activities become, which is reflected in studies conducted in various ethnic groups (Hill et al, 2000; Samuelsen et al, 1997; Laga-Jansen et al, 1992; Harzog et al, 1988; Yamell and Leger, 1979). In these circumstances, people are more likely to consider seeking help (Samuelsen et al, 1997; Burgin et al, 1994; Burgin, 1997; Osterman and Adelson, 1990).

Information gained from an urogynaecologist at a local NHS trust suggested a low percentage of Muslim women accessed services for UI. This may be due to a lack of knowledge about the condition or the sensitive nature of the subject. For example, Williamson (2001) found Asian women felt that health professionals were not interested in their problems and did not provide adequate support.

An inability to understand or fully understand spoken English can also make individuals reluctant to seek help (Fajgar, 1994; Bhogal, 1998; Antanov, 1995), and communication barriers can play a role in non-compliance to treatment (Turk et al, 1994; McAvoy and Bryant, 1998). Professionals are often used as interpreters in consultations - this can lead to potential details that the patient may not be willing to share being disclosed to other family members, or misinterpretation in medical consultations, which can lead to potential clinical mismanagement. It may not be possible to translate clinical and medical terminology accurately to a third language (Williamson and Williamson, 1995).

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with the ultimate aim of improved patient care.

Aims and methods

The aim of this study was to explore the religious and cultural influences on help-seeking behaviour and decision-making in South Asian Muslim women with UI. A qualitative exploratory design was used to understand values, beliefs, norms and experiences of Muslim women using a semi-structured focus approach. This consisted of broad questions the researcher wished to explore with each participant.

The research was carried out in the northwest of England. Potential participants were accessed through English for Speakers of Other Languages classes. The researcher had to be aware of the type of information that should be verbalised, as both sexes attended the sessions. Female group members were all given information packs and were asked to contact the researcher if they requested more information or decided to participate. The issue of communication was a major part in this study. The researcher is from an Asian background, and has the basic ability to speak Urdu. A local translation company translated all written information into Urdu.

All material in the packs was provided in English and Urdu. Manson et al (2003) identified that some people are able to verbalise other languages but sometimes reading that language can be difficult. As such, the researcher decided to explain the study and the consent procedure verbally to each participant. The consent form was signed when the participants understood their role, the role of the researcher and the purpose of the study.

Data was analysed using 'Framework' (Ritchie and Lewis, 2003), which comprises five main stages: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation.

Findings

All participants were Muslim women aged 21–70 years. They were all parous and suffered from lower tract symptoms. Countries of birth were India (four), England (four) and Pakistan (one). Six participants were Indian Muslim and three were Pakistan Muslim.

As this article is based on the religious and cultural aspects of themes identified in the transcripts, themes that correspond with the two will be discussed. The quotations are taken directly from the transcripts.

General influences on help-seeking and decision-making behaviour

Participants identified childbirth as one of the major causes of UI, followed by old age:

'I have heard old age causes UI but for me giving birth has caused me to leak. I was fine before then.'
(Aged 21, England)

They also suggested that poor knowledge of continence services was due to the lack of public awareness. This was a common theme:

'Media has a great influence on people. But there is no awareness about incontinence anywhere really.'
(Aged 28, England)

All participants stated they would seek help if they believed their UI had become more of a problem although this would be their interpretation and not anyone else's:

'Not bad [it's not bad] for me to tell a doctor about, these things happen and now it's a normal routine.'
(Aged 28, England)

Cultural influences on help-seeking and decision-making behaviour

Throughout the interviews, it was apparent that the older participants (35–70 years) did not attach as much importance to cultural influences as the younger participants (21–34 years). Younger participants

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Cultural influences on help-seeking and decision-making behaviour

(Aged 25, England)
 'But dad (he's not dad) for me to tell a doctor about, these things happen and now it's a normal routine, although this would be their interpretation and not anyone else's.
 All participants stated they would seek help if they believed their UI had become more of a problem.

(Aged 28, England)
 'It didn't have a great influence on people. But there is no awkwardness about incontinence anymore really.'

They also suggested that poor knowledge of continence services was due to the lack of public awareness. This was a common theme:

(Aged 27, England)
 'I have heard of age causes UI but for me giving birth has caused me to leak. I was the before then.'

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stated their parents had told them that examination by a male doctor was forbidden and religiously incorrect. However, none of these participants had read this information for themselves but strongly believed their parents' views were in fact religious obligations:

'I don't know if this is written in the book [Quran or Hadith] but I [am] sure it is.' (Aged 34, England)

Participants were unable to distinguish between cultural or religious behaviours. When questioned, one 34-year-old from England said, 'It must be written in the Quran or Hadith, I just have never read it myself.'

However, for the older participants there was a clear distinction:

'It's what people say, there is nothing wrong with going to see a male doctor, it's not religion.' (Aged 70, India)

The older participants identified embarrassment as having a greater influence over their behaviour than religion or culture:

'I would feel embarrassed going to a man doctor, Islam says you should go, if it's going to make you better. It's just embarrassing, telling aman.' (Aged 50, India)

All the participants identified religion and culture as two different influences but as the interviews proceeded, the differences appeared to be blurred:

'Well religion and culture play an equal part, they work together. Without culture I don't think you are following religion correctly.' (Aged 45, India)

Preference for male or female health professionals

When asked whether they would be prepared to disclose their UI to their GP (be they male or female), participants felt it would be a waste of their doctor's time. When given the choice, they stated they would prefer to tell their practice nurse, because they believed the nurse would not be as busy as the GP, although communication would be a problem:

'I would prefer to tell the nurse, they have more time, doctors are always busy but if I can't speak English how would I say it?' (Aged 34, England)

Older participants stated they had deliberately chosen an Asian GP because of their ability to understand and communicate in Urdu, and the similar cultural backgrounds. Due to their lack of command of English, four participants stated they would inform their GP:

'I would tell my doctor. It would be very embarrassing but at least I would be able to talk to him about it. I can't speak English so how would I tell the nurse?' (Aged 70, India)

Other participants said they would not tell their male GP about their UI under any circumstances, due to the fear of examination. One participant went further, stating:

'I wouldn't tell my doctor because he would want to examine me [pause] plus I don't think my husband would agree. A Muslim woman should not be examined by a male doctor.' (Aged 45, India)

Disclosure of UI

Failure to disclose UI to partners and relatives was a common theme, which was mainly due to the embarrassing nature of the subject. Women saw it as a subject area that should not be discussed with their husbands as it was a 'woman's problem' and discussing these issues was culturally wrong. Participants said they would only disclose UI to other female friends or family members. One participant felt she would discuss UI with her husband only if it got any worse. Others said they would never talk about women's problems with a male, including their partner/husband, due to concerns about their reaction:

'He would probably find it awkward. He is quite a strict Muslim and I don't think he would want to talk about it.' (Aged 45, India)

Religious influences on help seeking and decision-making behaviour

The importance of Islam in the lives of participants was emphasised:

'Life, death and health are from Allah. When Allah gives you an illness, you will receive cure from him too. I know Allah will not let me suffer.' (Aged 70, India)

Another participant stated:

'Illnesses are from God and God is the only source that will send you a cure too... you are being tested on every path.' (Aged 37, India)

All participants considered God (Allah) throughout the interviews and Islam was regarded as the most influential and important aspect of their life:

'My religion is not a religion but it is a way of life, this is what Islam means. It teaches me how to live my life.' (Aged 28, England)

Older participants said their religion had never stopped them seeking help:

'As women we should cover up, and not show our privates to anyone. Going to the doctor is a different thing, you are going for help.' (Aged 70, India)

However, the younger participants had a different view:

'My religion states I should not go to a male doctor, for ladies' needs. That is against my religion'. (Aged 34, England)

Participants were asked about Muslim women being examined by a male doctor:

'Muslim women cannot under any circumstances be examined by a male doctor, it is going against what is written in the holy book.' (Aged 34, England)

However, the older participants did not agree with this statement:

'It is not wrong, God has given you health, and illness is also from him [Allah] what we have to do is go and find treatment, whether it be [from someone who is] male or female.' (Aged 70, India)

Differences appeared to be related to age and country of birth. Younger participants who were British born identified examinations by male doctors as forbidden and were firm in these beliefs, while older participants did not think this was an issue, stating that religion did not restrict seeking help in any way. Older participants who had migrated from India or Pakistan also said in their country they could choose who they saw:

'If I was in my country [India] I can see man or lady doctor, because we have to pay. Here it is free, so we see whoever we can.' (Aged 70, India)

Participants were asked about the impact of UI on their religious duties:

'I drink less before I pray, [I also] go toilet before doing wadu.' (Aged 70, India)

Leaking urine or having a strong desire to urinate while performing prayers was another issue:

'Praying namaz involves standing, sitting and bending. Sometimes I do get a desire to pass urine. I don't leak or anything I just feel like I want to go.' (Aged 45, India)

Despite the impact on their lives, most women did not consider their UI to be a problem that would cause them to seek professional help.

Discussion and conclusion

Incontinence is gradually becoming an acceptable subject for open discussion (Walker, 1987; Horsfield, 1986; Glew, 1985), but our findings suggest this is not yet occurring in the Muslim population living in the northwest of England.

The inability to communicate directly with health professionals can be distressing, especially when approaching sensitive issues such as UI. In this study, family members always accompanied older participants to hospital, which provided a source of communication between professional and patient. However, this may cause additional problems if family members are unaware of some of the medical terms used – they may not be able to provide an accurate channel of communication between professional and patient, leading to potential clinical mismanagement.

UI can lead to social isolation (Breakwell and Walder, 1988). This was an issue in this study, as six out of nine participants either avoided social gatherings, familiarised themselves with the location of the toilets or totally avoided going out. Feelings of anger, guilt and frustration were expressed in the interviews, largely due to the lack of awareness and discussion about incontinence issues. These views have also been echoed in previous research with Caucasian, African, Chinese, Italians, Pakistani and Bangladeshi women of all age groups (Castro-Diaz et al, 2006; Huang et al, 2006; Milsom et al, 2006; Song et al, 2005; Novielli et al, 2003; Sze et al, 2002; Duong and Korn, 2001; Graham and Mallett, 2001; Scott, 1999).

Self-management was always considered prior to medical treatment, examples of this included restricting fluid intake, wearing pads and not attending social gatherings.

The severity of any illness determines whether an individual is likely to seek help or not (Shaw, 1999). Participants all stated they did not believe their symptoms were severe enough for them to seek help, although many wore pads daily. However, when explored further in relation to lower urinary tract symptoms and namaz, different views emerged. All participants either leaked urine or felt a strong urge to pass urine, which consequently made them rush prayers. They felt their symptoms caused a barrier between them and Allah – some stated it was a form of punishment and believed a cure was only possible through prayers. It is evident that urinary symptoms can have a devastating impact on well-being (Heit et al, 2006), especially when related to guilt and punishment.

In terms of religion, illness can be viewed as a punishment for the breach of religious codes and morals (Badawi, 1998).

Participants in the study all expressed similar thoughts to one 70-year-old from India, who said: 'Good health

and illness are both from God, and God is the only source of power that provides you with a cure.' These concur with the findings of Kelleher and Islam (1996).

Religious influences facilitated help-seeking behaviour, for example, some participants believed their religion stated that a woman should seek healthcare from a male doctor if a female doctor was not available. This finding is in line with Naqib al-Misri and Keller's translation of the Hadith (1994), which states that if 'a woman should seek help from a female doctor. If one is not available, she should seek treatment from a male doctor, with the consent and company of a male family member'. This is an example of a religious influence that can potentially restrict access to healthcare for Muslim women, especially if the health issue concerns 'women's needs'.

Muslim customs demand that women should not expose certain bodily parts to anyone except their husbands (Khattab, 2001).

This causes many problems for Muslim women who may be reluctant to attend for gynaecological tests. With regard to seeking help, the younger participants believed that their religious teachings stated

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Good et al. (2005) Novell et al. (2003) Bay et al. (2005) Chung and Kim, 2001; Graham and Miller,

Barbadeen women of all age groups (Garcia-Diaz et al., 2006; Huang et al., 2006; Wilson et al., 2006;

have also been noted in previous research with Caucasian, African, Chinese, Italian, Pakistani and

interviews, largely due to the lack of awareness and discussion about incontinence issues. These views

alone or jointly avoided going out. Feelings of anger, guilt and frustration were expressed in the

of nine participants either avoided social gatherings, familiarised themselves with the location of the

Usher lead to social isolation (Breakwell and White, 1999). This was an issue in this study, as six out

professional and patient, leading to potential clinical mismanagement.

items used – they may not be able to provide an accurate account of communication between

However, this may cause additional problems if family members are unaware of some of the medical

participants to hospital, which provided a source of communication between professional and patient.

approaching sensitive issues such as UI. In this study, family members always accompanied older

The inability to communicate directly with health professionals can be distressing, especially when

the northwest of England.

1999; Grew, 1995), but our findings suggest this is not yet occurring in the Muslim population living in

incontinence is gradually becoming an acceptable subject for open discussion (Walker, 1987; Horsfield,

Discussion and conclusion

modesty is required of women by Islam at all times. This was a strong influence and prevented some women from seeking healthcare.

It appears that the influence of culture, especially on the younger participants in the study, was as important as religious beliefs when it came to influencing help-seeking behaviour. For the participants in this study, their religion and culture had a great impact on them as individuals. Religion and culture had a very strong influence on their decisions regarding seeking help.

When women were informed about the possible treatment options for UI, there was a sense of disbelief among the participants. This clearly indicates the low knowledge of 'UI' within this group of women.

Limitations of the study

This study did not consider generalising the findings but was concerned with adding to our understanding of how culture and religion influence Muslim women when accessing services for UI. The sample size was small; this was due to the constraints of conducting a PhD, and women were reluctant to participate. To gain an overall picture the sample size would need to be increased and tested against those Muslim women who have sought help.

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IN PRESS

Title:

'The meaning of urinary incontinence from a Muslim woman's point of view'.

Author:

Chandbi Sange BSc (Hons) Nursing, PhD student

Professor Soo Downe BA (Hons) RM MSc (research methods) PhD

Gillian Thomson BSc (Hons), MSc (Distinction), PhD

Mr Simon Hill Consultant uro-gynaecologist

Correspondence:

Chandbi Sange

University of Central Lancashire

Department of Nursing

Preston

PR1 2HE

Email: CSange@uclan.ac.uk

chandbisange@yahoo.co.uk

The meaning of urinary incontinence from a Muslim woman's point of view

Author

Chandra Sanga BSc (Hons) Nursing PhD student

Professor Sue Downie BA (Hons) RM MSc (research methods) PhD

Olivia Thomson BSc (Hons) MSc (Dietetics) PhD

Mr. Sarah Hill Consultant uro-gynaecologist

Correspondence:

Chandra Sanga

University of Central Lancashire

Department of Nursing

Preston

PR1 3TB

Email: Chandra.Sanga@uclan.ac.uk

chandra.sanga@uclan.ac.uk

Abstract:

Aim: This paper presents the findings from a study describing Muslim women's perceptions of urinary incontinence and how Islam influences help-seeking behaviour.

Background: Urinary incontinence is a socially disabling condition that remains behind closed doors and not discussed. The impact of urinary incontinence on Muslim women has received little attention. Even less is known about the influence of religion and culture on help-seeking behaviour.

Method: Using a hermeneutic phenomenological study design 41 Muslim women were interviewed using a purposive sampling strategy.

Findings: Six categories were identified, which further generated three overarching themes. The first theme describes 'the balancing act', which examines participant's role in their family, balanced with how they managed their health. The second theme of 'family, religion and culture' described the fundamental aspect of the participants' lives, their family and religion. The final theme titled 'the meaning of illness' was their view of illness usually taking the Islamic perspective.

Conclusion: Based on the data, health care professionals in areas such as uro-gynaecology or general gynaecology, need to understand these women's perspectives through a dual lens: the biomedical model, and importantly, through the subjective experiences of the condition.

Keywords: hermeneutic, phenomenology, uro-gynaecology, urinary incontinence, Islam, Muslim women.

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Keywords: hermeneutic phenomenology, uro-gynaecology, urinary incontinence, Islam, Muslim women.

Summary statements:

What is already known about this topic?

- Urinary incontinence is a common condition affecting one in every four adults in the UK.
- Help seeking rates for urinary incontinence remain low
- Sufferers often do not seek help due to being labelled "abnormal" and due to embarrassment

What this paper adds

- Muslim women's anxieties about urinary incontinence are similar to the majority of the population
- Cultural and religious values influence help-seeking behaviours
- Health and illness for the Muslim woman is often viewed from an Islamic perspective, considering this would aid health care professionals to provide sensitive care for this group.

Implications for practice and/or policy

- Detection of urinary symptoms for Muslim women should begin in primary care, possibly via opportunistic screening
- Health promotion sessions are required to increase awareness of available help.
- To maximise the efficacy of these two initiatives, all staff who may come in contact with Muslim women should be educated in the religious and cultural factors that influence help seeking and treatment adherence.

What is already known about this topic

- Primary healthcare is a key element of the health system in the UK.

- Help seeking rates for primary healthcare are low.
- Patients often do not seek help for mental health problems.

What this paper adds

- Muslim women's experiences of seeking help for mental health problems.

- Cultural and religious factors influencing help seeking.
- Health and illness for the Muslim community in the UK.

- Perspectives, experiences, and needs of Muslim women with mental health problems.

- Implications for practice and policy.

- Detection of mental symptoms in the primary care setting.

- Health promotion activities for Muslim women.
- To maximise the efficacy of health promotion activities for Muslim women.

- With Muslim women should be encouraged to seek help for mental health problems.

Introduction:

In modern British society, attitudes towards many previously taboo subjects are rapidly changing. One of these former taboo subjects, incontinence is gradually becoming an acceptable subject for open discussion for sufferers and professionals. As a health concern, this condition is not life threatening. It is commonly reported that urinary incontinence (UI) is seen as a normal part of ageing. However, sufferers are likely to be isolated and lonely (Fultz and Herzog 2001). The psychological impact of UI was assessed by MaCaulay et al (1991). The results from this study identified that one-quarter of sufferers were as depressed and anxious as psychiatric patients. Suggesting that UI is an important topic to explore as it can have a profound impact on sufferers.

Background:

The prevalence of UI in the UK is under-estimated as many individuals are reluctant to seek help for a variety of reasons including shame, embarrassment and availability of treatment (Norton, 1988). The majority of epidemiological research on urinary incontinence has been conducted within the older white female population (Gray 2003). To date little is known about the prevalence of incontinence in non-white, younger populations.

Risk factors for developing UI have also been explored. These include smoking; pregnancy; parity; body mass index; ethnic origin; previous surgery; family history of childhood bedwetting; lack of exercise (Herzog et al 1994; Bump and Norton 1998). Evidence that race influences the overall risk of incontinence is mixed. For example, it has been identified that stress incontinence is more prevalent in Caucasian women (Bump 1993; Duong and Korn 2001; Novielli et al 2003); urge incontinence is more prevalent in black women and stress incontinence in white women (Sze et al, 2002). Reasons for these differences need further exploration. Parity is also a well-known risk factor for the development of urinary symptoms (Foldspang et al 1992; Milsom et al 1993). In general, the higher number of parities the more likely a woman is to suffer from UI.

Help seeking behaviour for UI remains low, due to the negativity associated with it. For a number of years researchers have been interested in factors that facilitate the use of health services. The focus of this research has been on how people make decisions about health issues and what factors influence help-seeking behaviours (Harding and Taylor 2002). In the literature many influences that encourage or discourage an individual from either seeking help or declining medical advice or treatment have been uncovered. Two such influences are culture and religion. According to Walsh (1998) religious and cultural beliefs can have positive influences on health by acting as a source of inspiration. However, Ahmed (2000)

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found they might also have negative influences, for example, when they are linked with guilt and punishment. Kelleher & Islam (1996) have stated that religious beliefs may create a sense of fatalism, a belief that someone or something other than the individual is in control. This identification is also called 'external locus of control' referring to individual's perception about the causes of events in his or her life (Rotter, 1966) which can affect health behaviours. Another likely influence is the effect of the condition on quality of life. However, it cannot be assumed that there is a simple linear relationship between severity of symptoms, quality of life, and help-seeking behaviour (Shaw, 1999).

Another likely influence on help-seeking behaviour is the opinions/advice of significant others, such as friends and family. However, discussing stigmatising conditions such as UI is not a norm (Shaw, 1999). Many sufferers are more likely to deny and conceal such symptoms, even from significant others.

Previous studies assessing the effects of UI on quality of life have explored the subjective experience of these conditions, but have rarely addressed the importance of ethnicity or the influence of religion and culture on individuals (Chaliha and Stanton, 1999).

Chaliha & Stanton (1999) found Muslim women reported more sexual and religious restrictions related to their UI than Hindus, Jews, Buddhists or Christians. Similarly, Wilkinson & Williamson (1995) found, Muslim women tend to have a higher parity rate therefore increasing the chances of developing UI. Cultural, language and religious characteristics can also introduce further problems (Wilkinson, 2001). Bhopal (1997) stated that the lack of understanding of conditions and embarrassment continue to be factors restricting people seeking help. A recent study by Doshani et al (2007) found a lack of knowledge about urinary incontinence as a condition within this group of women. The inability to read and write also causes a barrier as does the understanding of treatment options and advice. Simple translation of English into a target language is also a cause for concern. Wilkinson and Williamson (1995) found the translation of clinical/medical terminology into other languages could cause problems, as some words are not directly translatable.

A literature search undertaken prior to this study did not reveal any studies linking the impact and meaning of urinary incontinence with help-seeking behaviour in the Muslim population. Previous research has also stated religious and cultural beliefs can influence people when seeking health care (Kelleher and Islam, 1996; Walsh, 1998; Ahmed 2000). However, again, no studies have shown any comparisons relating religion and culture in Muslim women's help-seeking behaviour related to urinary symptoms.

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Understanding the impact of UI and associated factors within any religious or cultural group is necessary to indicate how health care providers may stimulate provision of, or improve, accessible and acceptable clinical or social support in this disease area.

The study

Aim:

This study aimed to explore the religious and cultural influences on help-seeking behaviour in South Asian Muslim women with urinary incontinence.

Design:

I intended to illuminate understanding and interpret the experience of leaking urine for Muslim women using a hermeneutic phenomenological design.

Hermeneutics adds the interpretive element to explicate meanings and assumptions in the participants' texts (Crotty, 2003). Communication and language are intertwined, and hermeneutics offers a way of understanding such human experiences, captured through language and in context (van Manen, 1997).

In line with Gadamerian hermeneutics, a reflexive journal was also maintained throughout the study.

Participants:

Due to the comparative element of this study participants were recruited from two main areas. Participants were recruited from the community setting (Muslim women who had not sought any medical help) and from continence clinic (Muslim women who had sought help). Demographic data of the study site was gathered on the percentage of Muslim women and on the areas where Muslims were more likely to reside. These data showed the largest minority ethnic groups in the Borough were of Indian (10.7%) and Pakistani (8.7%) heritage and lived in the inner town areas.

Seven community centres and access points within the identified areas were contacted for an informal meeting regarding the study and recruitment. Posters were placed in these centres for recruitment purposes.

For those participants who had not sought help recruitment took place in ESOL (English of speakers of Other Languages) sessions, where a 5-10 minute talk about the project was given. For those participants who had sought help recruitment took place in continence clinics. Information packs were distributed that included an invitation letter, information sheets, consent forms, demographic data questionnaire and flyer about the study.

Participants were purposively selected from the various settings:

Understanding the impact of L1 and L2 on health is necessary to understand how health is maintained and how it can be improved. It is necessary to understand the clinical and psychological aspects of health.

The study

This study aimed to explore the impact of L1 and L2 on health in South Asian Muslim women with urinary incontinence.

Design

I intended to illuminate understandings and experiences of South Asian Muslim women using a hermeneutic phenomenological approach. Hermeneutics adds the interpretive dimension to the phenomenological approach. Participants' texts (Kenny, 2001) were analysed using a hermeneutic approach. The hermeneutic approach is a way of understanding the world through language and in context (van Manen, 1990). The hermeneutic approach is a way of understanding the world through language and in context (van Manen, 1990). The hermeneutic approach is a way of understanding the world through language and in context (van Manen, 1990).

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- 18 years and over
- Have experienced some form of urinary incontinence
- Muslim women
- Within the geographical area
- Had sought medical help or had not sought help.

Data collection:

In-depth interviews were undertaken. This method was chosen due to its flexible and exploratory nature, and because it allows for the detailed study of participants' views on the subject matter. Interviews were audio-recorded and transcribed.

The guide for the first set of interviews focused on the participant's general knowledge of UI, and the effects of UI on daily living (Muslim women who had not sought help). Aspects of religion and culture were also explored around the issues of UI, and influences on help-seeking behaviour. Data arising from these interviews were used to adapt the topic guide for the second set of interviews (Muslim women who had sought help).

Ethics:

Ethical approval was sought and gained from four committees; a) Lancashire and South Cumbria Agency (LREC); b) Research and Development at Royal Blackburn Hospital; c) Faculty Ethics Committee at University of Central Lancashire; and d) Primary Care Trust (PCT) at Blackburn.

Participants were all informed that their participation in this study was voluntary, and refusal to take part or stop participating would not affect any medical treatment. Information provided was both verbal and written information in English and Urdu.

Due to the sensitive nature of the subject, participants were informed that findings would be disseminated at conferences, published in articles and finally in a thesis. Confidentiality and anonymity would be maintained through the use of pseudonyms, and no information that could identify them would be disclosed.

Data analysis:

The analysis was based on core hermeneutic phenomenology principles as described by Cohen et al (2000; pg 76-82).

Immersion oneself in the data: The data were read over several times, to form some initial interpretation, and to identify essential characteristics in each interview for each participant.

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Data collection:

• Had sought medical help or had not sought help.

• Within the geographical area.

• Muslim women.

• Have experienced some form of urinary incontinence.

• 18 years and over.

Data transformation/data reduction: Relevant and non-relevant issues were drawn out of the interviews to place together under similar categories.

Thematic analysis: Line by line coding was carried out for the thematic analysis without losing sight of the meaning (Cohen et al, 2000). Themes and sub-themes were identified, through reading each statement and line. This enabled extract passages to be taken from the whole data set and examined against each statement and themes.

Writing and re-writing: The understanding and insights of the meanings, from parts to whole and vice versa occurred through a reflective process of writing and rewriting.

Findings:

Of 103 women approached, 41 agreed to take part. This proportion was the same in the two groups of interest (help-seeking or not). The gap between the numbers and the number that agreed to take part might be explained by a number of factors, including time, commitment, language, and possible embarrassment about the condition itself.

The age range consisted of 18 years and over which allowed exploration of practices and beliefs among younger and older Muslim women. This provided multiple perspectives to illuminate the phenomena under study, which is a valued aspect of interpretative research (Cohen et al 2000).

Through my interpretation of the texts six categories emerged 'Me, my family and I'; 'My religion my identity'; 'It's the norm'; 'It's like a hush hush thing'; 'It's not cancer' and 'Get myself checked out'. The first two categories relate to participants belief system and practices. The next three categories relate to the subject of urinary incontinence.

'Me, my family and I'

I have titled one of the fundamental categories to emerge as 'Me, my family and I', since Muslim women in this study stated that their life and being was centred on their families.

'Family is very important to me, without my family I wouldn't be anywhere, nothing takes priority over it, but Islam and worshipping Allah. You have to think of them first and then yourself' (Naila, 26 years old).

Participants all lived in predominantly Muslim areas, where many dressed the same, spoke a common language, and had similar views, values and practices. Residing in such areas allowed a continuity of similarities to be maintained.

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'This area here is full of Muslim people. We are all the same...It is nice, I know this is not our country, but the people living around here are all the same, they are all Muslims' (Tayiba 63 years).

The family, the community and the society these women resided in all impacted on their view of life and how they react to each situation in their life.

'My religion my identity'

Participants assigned great importance to their religion. Daily tasks, and their whole lives were based on religious teachings, and teachings of significant others.

'Islam is a way of life, God teaches us how to live, do no harm and no one will harm you. I have strong belief in my God...All good and bad are from God' (Khalida, 42 years old).

Islam provided a protection for many participants away from the wider society. This was related to the recent terrorist attacks, which made some feel personally targeted. Many participants reported that their religion was a peaceful religion and violence was not tolerated, due to Islamic extremists they had experienced racial hatred.

'Islam is a peaceful religion ... just cause I wear a scarf doesn't make me a bad person' (Aisha 28 years old)

Many had turned to their religion as a form of protection and belonging together. Islam had therefore become even more entrenched as 'their identity'.

'Myself...Muslim Indian I think, I am British but I suppose no matter how much you want to fit in the first thing people see is your colour... no matter how much we try and fit in, we will never be them' (Khalsoom, 26 years old).

Participants lived in accordance to their religious beliefs. Equality and care for others was the two roles that participants in this study assigned to being a Muslim woman, although worshipping Allah was the main and fundamental role.

'The men are always thought as higher...I don't think that is really religion but culture they way you have been bought up in' (Saleema, 35 years old).

The above two categories described the fundamental part of the participants' lives, aspects of which participants appeared to appreciate and discuss freely. However, when discussing the topic of urinary incontinence the participant's body language changed considerably. In this case, lack of eye contact, embarrassment and shame was noted. The following categories expand on this observation.

'It's the norm'(?)

Normalisation of urinary incontinence based on age and parity was common by the women in this study.

'Having so many children is the first thing plus I am old now' (Sobia, 58 years old).

Some participants believed that urinary incontinence was not a result of childbirth but other medical conditions.

'I tend to cough a lot because I have asthma, and that is when I tend to leak more' (Arifa, 37 years old).

Self-management strategies were frequently adopted by these women such as fluid restriction, use of regular sanitary protection, frequent toileting and restricting social movement.

'I wear pads every morning without fail now. You can guarantee if one day I did not wear a pad that would be it, I would totally leak everywhere...I always carry some in my handbag' (Zorah, 52 years old).

'I have to go to the toilet ever couple of hours, whether I want to or not' (Shahista, 54 years old).

Despite the fact that women tried to normalise and self-manage their conditions, their UI was identified to affect them especially in the company of others. Many of the women interviewed in this study isolated themselves from others for fear of leakage and odour.

'I have changed a lot I use to be an out going person...but it has all changed...I just feel maybe they may smell it' (Fatima, 70 years old).

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'I went back every morning without fail now. You can guarantee if one day I did not wear a pad then would be if I would totally leak everywhere. I almost carry some in my handbag' (Zinah, 52 years old).

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'I have changed a lot I use to be an outgoing person...but it has all changed...I just feel made very small' (Fatima, 70 years old).

Lack of media coverage was also a barrier to participant's knowledge about urinary incontinence. Participants felt Asian channels and channels in general do not address the issue of UI.

'Incontinence is not even talked about I mean you don't hear it on telly do you...I mean the media influences a lot of people but there is no knowledge or awareness about incontinence' (Aisha, 28 years old).

Participants were asked about the impact of leaking urine whilst performing prayers. At this point, some participants felt they had committed 'sin', by rushing prayers, leaking whilst under ablution or, indeed, having not prayed for a number of years due to UI.

'As a Muslim you need to be clean all the time, if I leak urine, how can I pray, you need to be clean to pray... I am so ashamed of what I am saying ... if I have rushed prayers then ...I never looked at it in that way' (Arifa, 37 years old).

For a number of these women leaking urine or rushing prayers became a sense of punishment by God.

'I feel like I am being punished for something ... I feel I can't pray because of this problem' (Nazia, 54 years old).

This change in perception appeared to be linked to a realisation of the impact of leaking urine during the performance of religious obligations. Some viewed leaking urine as a sinful act that could only be remedied by medical attention, especially if UI came between them and their God, although further barriers were discussed.

'It's like a hush hush thing'

Many participants in the study stated that they would only disclose their urinary symptoms to female family members because it related to the female genital area. Disclosing or discussing female health issues with males was not considered culturally appropriate.

'It shouldn't be talked about, because it is like talking about something so personal or private. A woman should not talk about this to anyone' (Saajida, 45 years old).

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incontinence. Participants felt Asian channels and channels in general do not address the issue. Lack of media coverage was also a barrier to participant's knowledge about urinary

'No I have not told any one at home...they don't need to know' (Sofia, 37 years old).

Indeed, discussing UI with male relatives or male health care professionals was frowned upon within the Muslim culture.

'No way! It is not a thing to tell your husband at all...my husband does not even know I have incontinence problems' (Saleema, 35 years old).

One of the key barriers to disclosures of UI symptoms was the likelihood of pelvic examination, which many feared.

'Going to a man is against my religion as no man but your husband should see you in that condition' (Salma, 26 years old).

In reality, there is no formal restriction placed on Muslim women in the religious texts when seeking healthcare (Al-Misri and Keller 1994). If no female doctor is available, healthcare should be sought from a male practitioner with the permission and accompaniment of her husband or father. This religious fact did not seem to be known by a number of the participants.

Participants stated that approval from their husband was of great importance to them, especially where examination was necessary. However, this introduced further problems as it would mean disclosure of their symptoms, therefore many refused to seek help.

'It's not cancer'

Participants appeared to subconsciously maintain a hierarchy of their medical conditions. For example, those who suffered from other conditions such as asthma, diabetes, angina or hypertension felt that leaking urine was the least of their problems. This was also related to the normalisation of this condition.

In the same way that people hold beliefs about health they also hold beliefs about illness. Participants believed that ill health was a test from God or a punishment for their sins. Muslims understand illness, suffering and dying to be a part of life and a test from Allah. In Islam, illness is also regarded as a test of how strongly a person believes in God.

The first set of data was collected from the participants in the first condition.

Indeed, despite the fact that the participants in the first condition were not aware of the purpose of the study, they still showed a significant increase in the number of correct responses within the first condition.

The second set of data was collected from the participants in the second condition. This set of data was collected from the participants in the second condition, who were aware of the purpose of the study.

One of the key findings of the study was that the participants in the second condition showed a significant increase in the number of correct responses within the second condition.

Going to a more general level, the results of the study suggest that the participants in the second condition showed a significant increase in the number of correct responses within the second condition.

In reality, there is no formal distinction between the two conditions. The only difference between the two conditions is that the participants in the second condition were aware of the purpose of the study, while the participants in the first condition were not. This difference is the only difference between the two conditions, and it is this difference that is the focus of the study.

Participants stated that they were aware of the purpose of the study, and they were aware of the fact that they were being tested. This awareness was the only difference between the two conditions, and it is this difference that is the focus of the study.

It is not clear, however, whether the participants in the second condition were aware of the fact that they were being tested. This awareness was the only difference between the two conditions, and it is this difference that is the focus of the study.

In the same way that people who are aware of the purpose of the study show a significant increase in the number of correct responses, people who are not aware of the purpose of the study show a significant increase in the number of correct responses. This is the only difference between the two conditions, and it is this difference that is the focus of the study.

'Allah states when you are ill, he will send you a cure whether that is in the form of a doctor... if something is coming between me and my Allah, then Allah has give you that strength to go out and find help' (Farhat, 46 years old).

With regard to seeking healthcare for incontinence, there was a clear relationship between symptom severity and help-seeking behaviour. Participants reported that the reason UI would be disclosed to a doctor was 'if it got worse', or if there was 'fear of a serious underlying cause', or if UI led to 'restrictions on religious obligations'.

'I mean I will go to the doctors if I thought my incontinence got any worse...If I can mangle it I will manage but if I cant I will do something about it' (Abeeda, 57 years old).

Almost half of the participants presented a rationale for not seeking help. The most repeated was that incontinence is age-related, and their condition was manageable. Leaking urine for these women was mainly understood as something related to their genital area; therefore seeking healthcare was not comprehensible in terms of their cultural and social context, therefore forcing many to self-manage.

'Get myself checked out'

All fourteen participants who had sought help did so because their symptoms had become progressively worse, and had created a barrier between them and their religious obligations. The process of seeking help began through their General Practitioner.

'I told my doctor because it was getting worse, sometimes I can stand up and it use to come out' (Khalida, 42 years old).

Participants that had accessed continence services generally felt unhappy. Reasons usually related to the inability to communicate directly with healthcare professionals. This further introduced problems as many of these women became non-compliant to treatment plans.

'The exercises don't work, I wanted an operation...I don't do the exercises' (Hameeda, 46 years old).

Surprisingly even when conditions of leaking urine had improved considerably as a consequence of formal help-seeking, some women felt guilty about going against what they perceived as religious prohibitions. As the physiotherapist and the nurse specialist were both females, there were no perceived religious restrictions. However, both the urologist and the

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uro-gynaecologist were male. Examination by these male doctors placed those participants who saw them in awkward circumstances.

'I wouldn't see X because he has to examine me...it is wrong for us Muslim to be checked by a man' (Nazia, 54 years old).

Those who had seen the specialist consultants stated they had 'done wrong' by their religion, and would sincerely ask God for forgiveness. Exposing themselves to male doctors for these women was a sin, a sin that may not be forgiven. This viewpoint only became apparent as the interviews progressed. Many of the participant especially the older women, had stated that exposing oneself to a male was totally against their religious beliefs; however the inability to worship their God was a much bigger sin. Therefore, to maintain a balance, a male consultant had examined participants that had sought help.

Synthesis and discussion:

An understanding of what these women were describing required an acknowledgement that their culture, which was based on Islam and Islamic teaching, was essential for them. This filtered through their thinking, their behaviour, their beliefs and practices. It influenced every aspect of their lives, thus contributing to their understanding of life and their interactions with others.

Through the process of engaging with the data, it became clear that the women were describing a 'balancing act'. This included their perceived role as Muslim women, their family, continuing religious and cultural practices, and their health, in a country in which most of them felt alienated. Many of the participants managed multiple roles, which meant their health was sometimes overlooked. Their lives revolved around their families, where Islam became the centre of all acts and practices.

The balancing act

The theme titled the 'balancing act' examines these women's roles in their family, balanced with how they managed their health. The meaning of UI for these women was a complex 'whole', where the 'parts' that constructed the 'whole' were the family, religion and culture, health, illness and wellbeing. The process of understanding the findings entailed a constant movement from the 'whole' to the 'parts', described by Gadamer as the '*hermeneutic circle*' (Gadamer, 1987; pg 87).

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Through the narratives, it became apparent that the way these women managed their condition(s) and their life was through the influences of their religion, culture, and their family. This allowed participants to normalise their lives through one of the following responses: self-managing and becoming lay experts; adopting the 'sickness role'; or seeking professional help once this could be interpreted as sanctioned religiously.

Family, religion and culture

The data confirmed that family was the backbone for these participants. Even though many were adapting to the 'nuclear' family, the concept of the extended family remained more influential. This related to a sense of belonging and 'wantedness'. It seemed to be intensified by a feeling of rejection by the British society, due to religious belief. For such reasons many of the women in this study identified themselves as primarily Muslim. Islam became their identity, a lens that had become so powerful that, through their narratives, a strong sense of 'protection or rejection' was evident.

Participants made meaning out of this situation by maintaining practices which were usually reinforced through culture and family, and that were originally embedded with their religion. Continuing with such practices allowed many to feel 'part' of a group, permitting a sense of belonging in a country that was alien to them, a country that, they felt, had not welcomed them due to their religious beliefs. Their identity, their attire, their speech and their own environments appeared to be very overtly Islamic. Ahmed (1996) refers to this as a '*biraderi*', a system that exists within the South Asian communities offering an important source of identity and support.

Women talked about the problems they faced when arriving into the UK from countries such as India or Pakistan, where the way of living was different from in the UK. They feared not only rejection by the British society, but also rejection in the communities they lived in. This appeared to be complicated by a lack of access for those outside the community. At the same time as closing themselves away from British people, some of the participants felt 'judged' by them. Many had appeared to create boundaries between themselves and the wider British society. Consequently, some seemed to have alienated themselves from seeking health care from professionals.

Participants perceived their roles as Muslim women to be child-bearers, carers and nurturers. Employment and education were not the norm. This set of norms provided reinforcement towards the stereotype of 'traditional Asian woman' (Naidoo and Davies 1988). Taking up employment and wearing Western clothing took on both religious and cultural overtones: it was seen as un-Islamic and un-Asian.

The meaning of illness

Illness or being well for an individual is a subjective interpretation, viewed from that individual's perspective. 'Health' and 'well-being' for the 41 participants in this study occurred through a complex interplay between personal experiences and cultural factors, including language and religion. Generally, 'health' referred to the absence of illness or regular taking of medication.

Health was viewed through the Islamic perspective. Many participants made statements such as: *'good and bad health is from Allah, who was the only one that would send them a cure'*.

From their religious perspective, Muslim women's recovery from any condition or deterioration was *ONLY* in the hands of their God, because God meant it to be that way. According to Khayat and Haytham (1999), health within the Islamic framework is described as a *'state of complete physical, psychological, social and spiritual well-being'*. This definition is not different from the WHO definition of health. The additional element for Khayat and Haytham was spiritual health, which they considered the most important aspect. As the prophet Muhammed (saw) stated *'Allah does not look to your bodies or your forms, but rather He looks to your hearts'* (Sheikh and Gatrad, 2000, pg 30). For this reason many Muslim communities discard 'depression' as an illness, as it is seen to be related to a lack of faith (Fonte, 2005).

Health and well-being are understood to be the greatest blessings to have been given to people and for which they are accountable to Allah (Khayat and Haytham, 1999). This implied that care should be taken to rid the body of illness and disease as much as possible. However, 'illness' and 'disease' were not related to leaking urine by many participants. There was a belief that UI was a normal part of ageing and childbirth, as opposed to a condition (Doshani et al 2007). Healthcare professionals reinforced this, as some of those who had sought help reported that primary/secondary healthcare staff implied that UI was a normal consequence of giving birth, and ageing.

Real illnesses, for these women, were those where medication was prescribed. Some participants were commenced on oxybutynin (prescribed medication for urinary incontinence) although they believed it was to clear urinary tract infections and not for incontinence. Therefore UI was interpreted as a 'condition' that was manageable, and not a significant or a real illness.

Conclusion:

There is vast amount of literature exploring why people from ethnic minority backgrounds do not access health services, however understanding of cultural and religious influences on this process is limited. The lack of empirical research means that professionals may have only informal insights into cultural and religious influences on the management of urinary incontinence.

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incontinence.

The understanding of urinary symptoms is based on embodied physiological processes, influenced by socially expected norms. It is only when such norms are violated, and when women cannot effectively balance the family and the illness, that social and psychological consequences arise. It is therefore imperative to understand cultural influences that are embedded within each societal expectation, belief, norm, practice and value.

This paper is presented as part of a thesis specific to urinary incontinence and Muslim women.

Limitations of the study:

A major limitation of a hermeneutic phenomenological study is that the findings only present one interpretation of the data and therefore cannot be generalised. The sample size in a hermeneutic study is typically small and is a way to observe the richness and complexity of the experience and to provide in-depth knowledge on the given phenomena.

Due to demographic data of the study area, most participants were Indian, Pakistan or British. However, I did recruit two Muslim women who had originated from Kenya. I was not able to include women from other religious groups, therefore this study contains one specific religious group, cultural practices pertaining to that group, and one view of 'being'. Including other religiously orientated groups in future studies would be important as their views and practices can be explored to deepen our understanding of the impact of UI in these groups.

Despite these limitations, it cannot be denied that the depth of information given by participants in this study provides valuable insights into their lived experiences of UI, their religion and their roles as Muslim women.

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